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ABSTRACT

This report compares personal assistance services to enable independent living for people with disabilities in Sweden, West Germany, and the United States. The report focuses on kinds of personal assistant services available, laws governing these services, the extent to which these services are met by each country's social security and welfare system, and how laws and services relate to the concept of independent living. After an introduction about personal assistance services in general, the second section looks at independent living movements in these three countries, and the third section at obstacles of comparing social welfare programs. The fourth section describes personal assistance services in Sweden and covers social security and welfare, social benefits for inhome personal assistance services, services relating to education and employment, administration and structure of programs, and evolution of the Swedish system of services. The following section looks at similar services in the United States. Covered are antidiscrimination law and the right to the least restrictive environment, social security and welfare law, federal legislation providing funding sources for personal assistant services, services relating to education and employment, program administration and structure, and program evaluation. The sixth section describes services in West Germany and addresses: social security and welfare, benefits for inhome personal assistance, education and employment services, program administration and structure, and program evaluation. A concluding section lists principles passed by a 1989 European Conference on Personal Assistance Services for Disabled Persons and highlights advantages and disadvantages of each country's programs. (61 references) (DB)

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Personal Assistant Service Programs

in Germany, Sweden and the USA

Differences and Similarities

by

Theresia Degener, LL.M.

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Preface

The present LL.M. thesis describes and compares certain services for disabled people in three different countries. These have been called inhome-support services, attendant care services, home services, community-based services, personal assistance services and more. Basically all these names describe services which enable disabled people with functional limitations to live in the mainstream of society. There are different understandings with respect to the scope of these services, the tasks involved, the delivery model, the role of the disabled person and other aspects. Sometimes the name relates to a certain service paradigm as is the case with "personal assistance service". This term has been chosen by disability activists and stands for those services that are designed to enable independent living (IL) for disabled people, which itself is a concept with several meanings. But "in essence, IL, means allowing people with disabilities to live as they choose in their communities, rather than confining them in institutions."[1]

In this thesis the term personal assistance services is used and the implied service paradigm also serves as the measurement for comparison. The leading questions of my study have been: (1) What kind of services for disabled people area available in Sweden, West Germany and the United States, which could be called personal assistance services in a broader sense? (2) What are the laws governing these services? Is the need for these services met by each country's social security and welfare system? (3) How do the laws and the services relate to the concept of independent living?

The study can only be seen as a first step to a legal examination of the subject of personal assistance services to disabled people. Therefore, appeals procedures and similar aspects of social programs providing those services are not covered by this thesis.

Another point that should be mentioned is that I have studied law and lived in the United States as well as having completed my first law degree in West Germany. But I have never been to Sweden, neither do I speak the language. Thus, my study with respect to this country had to rely on materials published in English or in German. Shortcomings in my description of the Swedish system might be a result of these circumstances.

Nevertheless, I found it important to include Sweden in the comparison, because it represents an extreme form of social welfare state in which these services to disabled persons have a long history. At the other end of the scale, the United States represents a country with less of a social safety net for its citizens, but which has a strong independent living or advocacy movement led by disabled persons.

I have been motivated to undertake this study because of my personal involvement in the West German disability movement. An equally strong motivation, however, is the recognition that personal assistance services are essential for the future. The growing number of people in need of these services requires new directions in social policy and law.

The present thesis would not have been possible without the kind support of many people. Therefore I finally want to express my thanks to all the groups and individuals who encouraged my study. Special thanks to the World Institute on Disability, the Dis-

ability Rights Education and Defense Fund, the staff of the Boalt Hall Faculty, to Barbara Duncan of Rehabilitation International and above all to my academic adviser, Professor Stephen Sugarman.

I also wish to express my gratitude to the Foundation "Stiftung zur Förderung körperbehinderter Hochbegabter" of Liechtenstein who gave the financial support for the publication of the thesis.

[1] Crewe N.M., Zola I.K. (1987) *Independent Living for Physically Disabled People*, Jossey-Bass, San Francisco, London, at ix

I. Personal Assistance Services for Independent Living of Disabled People

A. Independence and Disability

Disabled people are frequently described as a group precluded from the "American Dream of Independence".[1]

In general what is meant by this is that disabled persons are segregated from the mainstream of society and unable to lead a self-determined life. For many nondisabled persons, the concepts of independence and disability do not go together.

Disabled people are frequently described as a group precluded from the "American Dream of Independence". In general what is meant by this is that disabled persons are segregated from the mainstream of society and unable to lead a self-determined life.

The concept of independence, however, can be defined in various ways. For many it implies economic independence as opposed to being on social welfare rolls. Others might associate independence with being one's own employer instead of someone else's employee or with independence from gender-based expectations. For disabled persons the concept of independence has many meanings and, among others, depends on the kind of disability involved. For example, for wheelchair riders architectural barriers such as steps and narrow doors create segregation and dependence. Many disabled persons are dependent on social welfare or social security because of lack of education, inaccessible workplaces, or just attitudinal barriers which prevent them from achieving their own income.[2]

A vast number of disabled persons need technical or personal assistance in their daily living. From a nondisabled perspective, these persons are dependent and this view reflects the societal view of disability as a tragedy, as a status of dependence and inactivity.

This long-established stereotype of disability is now being challenged in the United States as well as in Europe with the rise of disability movements which emphasize civil rights and equal protection instead of charity and good will as the basis for disability policy.[3]

For the members of these movements the concept of independence does not imply carrying out daily activities without personal or technical help. Judy Heumann, one of the U.S. activists of the disability movement and presently Co-Director of the World Institute on Disability, once defined the concept of independence for (physically) disabled persons: "To us, independence does not mean doing things physically alone. It means being able to make independent decisions. It is a mental process not contingent upon a 'normal body.'[4]

Thus, a person's need for personal assistance due to disability does not preclude the possibility of independence. According to this view, one of the reasons

This long-established stereotype of disability is now being challenged in the United States as well as in Europe with the rise of disability movements which emphasize civil rights and equal protection instead of charity and good will as the basis for disability policy.

why disabled persons are foreclosed from the mainstream of society is the lack of personal assistance services.

"People have often gotten help from others but it was given in the context of duty and charity. Help in the context of Independent Living is instead given within the framework of a civil right and a service under the control of the recipient—where, when, how and by whom."

B. Personal Assistance Service as a Key to Independent Living.

Not all personal assistance, however, guarantees independence. Rather this depends on its form and its scope.

Provided in a traditional institution or nursing home, personal assistance inevitably creates dependence. The disabled person is completely subject to the institutional rules and schedules of treatment. His/her entire daily living arrangements are "taken care" of. In institutional settings disabled persons thus lose control of their personal care.

Dependence can be created outside institutions as well, if personal assistance is provided as a matter of charity of family duty. Irving Kenneth Zola, prominent member of the U.S. disability movement,[5] points to this aspect of personal assistance: "People have often gotten help from others but it was given in the context of duty and charity. Help in the context of Independent Living is instead given within the framework of a civil right and a service under the control of the recipient—where, when, how and by whom."[6]

To define the scope of personal assistance for disabled persons is a difficult enterprise because it implies a variety of activities, depending on the disability involved, which itself is a difficult term to define.[7] The World Institute on Disability describes personal assistance tasks as "ones that individuals would normally do for themselves if they did not have a disability". Included are: "1) personal maintenance and hygiene activities such as dressing, grooming, feeding, bathing, respiration, and toilet functions, including bowel, bladder, catheter and menstrual tasks; 2) mobility tasks such as getting into and out of bed, wheelchair or tub; 3) household maintenance tasks such as cleaning, shopping, meal preparation, laundering and long term heavy cleaning and repairs; 4) infant and child related tasks such as bathing, diapering and feeding; 5) cognitive or life management activities such as money management, planning and decision making; 6) security-related services such as daily monitoring by phone; and 7) communications services such as interpreting for people with visual disabilities.[8] This definition reveals that personal assistance as a tool for independent living is considered to be applicable to all kinds of disabilities. One could describe personal assistance as a substitute for any functional limitation as a result of disability.[9]

C. Personal Assistance Services as a Social Policy Issue

Personal assistance services for disabled persons are not a recent invention of the modern disability movement in Europe or the United States. "Care for the disabled" has long been an arena of concern of social welfare and public health agencies. Initially, "care" for disabled and elderly persons who had no family support was provided in institutions such as almshouses, and later hospitals or nursing homes. "Attendant care" and "inhome health services" emerged in Sweden during the 1930's and in the United States and West Germany after World War II.[10]

During recent decades, those social services providing personal assistance for disabled and elderly citizens in their homes and within private environments have gained increasing attention within the fields of social policy and public health.

Besides the voices from the disability movements, social changes in Europe as well as in the United States increased the demand for expanded personal assistance services.

Improvements in medical technologies including surgical techniques and medication now allow more persons to survive injuries or life threatening diseases, or, simply to live longer.

Demographic changes have increased the societal proportion of elderly persons, while at the same time the family structure has undergone modifications. Growing female participation in the labor force, rising divorce rates, and the trend toward smaller family units contributed to the family's decreasing ability to provide regular personal assistance to disabled family members.

At the same time, deinstitutionalization movements came into being on both continents, strongly insistent that alternatives in community-based settings had to be developed.

In addition to this growing demand for public personal assistance services, budgetary cuts of the late 70's and early 80's caused governments to be

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In the United States during the late 60's and early 70's a growing disability movement shaped the debate about such social services through the creation of what is called the independent living movement. Its influence on Sweden and West Germany as well as other countries through international networking among domestic disability movements is significant.

In all three countries social policy makers and legislators are now confronted with social movements that have adopted the subject of personal assistance for independent living as their cause. The various legal frameworks and social programs concerning these kinds of services provided by each country shall be explored and compared in this thesis.

II. Independent Living Movements in the United States, Sweden and West Germany

A. Origin and Concepts of the American Independent Living Movement

Personal assistance services differ from traditional "attendant care" with respect to the notion of disability, the service setting, the service delivery method and helping style, because of values and philosophy of the independent living movement.

1. The Concept of Equality

The independent living movement was founded by U.S. disabled activists who were influenced by the growing struggle for equal opportunities of the civil rights movement and the feminist movement in the late 60's.

The independent living movement was founded by U.S. disabled activists who were influenced by the growing struggle for equal opportunities of the civil rights movement and the feminist movement in the late 60's. A number of disabled persons had been active in these movements and they came to see their disability in the same political context as black people viewed their race and feminists their gender.

A number of disabled persons had been active in these movements and they came to see their disability in the same political context as black people viewed their race and feminists their gender.[11]

Disability was reconceptualized by the activists as a different state of being rather than a tragedy. It was recognized as a basis of discrimination by non-disabled persons which took different forms, such as architectural and educational barriers as well as prejudice.

Similar to the black people's civil rights struggle, they begin to demand equal protection under the law and equal opportunity in American society. However, disabled activists from the start proposed an equality concept that demands that society undertake special efforts in order to equalize opportunities for its disabled members. Unlike race and in most cases gender, disability was immediately acknowledged as a difference which would not totally become irrelevant once past discrimination and wrongs had been remedied.[12] No meaningful equal opportunity for (severely) disabled persons can be achieved without accommodations and assistance. Thus, disabled activists began to promote an equality concept that is based on the needs of all members of society, rather than on the "neutrality" concept of equal treatment.

According to this equality mode, nondiscrimination with regard to disabled persons requires the removal of barriers that exclude groups of disabled persons and some reasonable accommodations in order to eliminate disadvantages that have been placed on people because of their disability. Installation of ramps and modifications of working places, for example, are nondiscrimination requirements because access denial would have the effect of a denial of equal rights.

According to this concept of civil rights for disabled persons, individuals are to be entitled to lead a self-determined life with equal opportunities within the general community. This in turn requires provision of independent living services to assure disabled persons necessary assistance. Put different-

ly, social rights or benefits such as income maintenance and medical are considered as prerequisites for the performance of civil rights by the independent living movement.[13]

Thus, from the beginning, the independent living movement has been concerned with civil rights and benefits at the same time.[14]

2. The Influence of Other Social Movements

The independent living movement proclaims a concept of social services which also incorporates the values of other social movements beyond the civil rights movement. These are the deinstitutionalization movement, the consumerism and self-help movement, and what was called the demedicalization movement.[15]

The deinstitutionalization movement in the United States started out as a community mental health movement. Normalization and community living were put forward as the guiding ideology for services for mentally disabled persons. Deinstitutionalization principles emphasize the therapeutic as well as moral or ethical value of people with disabilities having ordinary life experiences.[16] One principle flowing from this ideology that became important to the independent living movement is the principle of "dignity of risk".[17] It is based on the notion that the right to normalization and mainstreaming implies the right to experience failure. Without this experience the disabled person is said to lack true independence; the right to choose between good and bad. The principle also finds the notion of sheltered (segregated) settings as antithetical to the development of disabled children and adults.

The significance of the demedicalization movement was that it challenged the dominance of the medical profession. Based on Ivan Illich's analysis[18], that too many social problems are 'medicalized' and the conviction that individuals should take up more responsibility for themselves, it supports the view of the disabled person as the best expert on his/her own disability. As opposed to the medical and vocational rehabilitation model, (whereby professionals determine what is best for the disabled "patient") the disabled persons is considered a consumer who is responsible for his/her own life and medical well being. As a principle of consumerism, the disabled consumer has a right to information and sovereignty.[19]

3. The Independent Living Model of Personal Assistance Services

The independent living model rejects the paternal notion of personal, professional care developed under the institutional and traditional inhome health service models. Rather it is based on the philosophy that to be independent implies empowerment and self-direction. Thus, an appropriate personal assistance service would adhere to the principle that users have "the opportunity, if desired, to exercise as much control as they are capable of handling over the direction and provision of these services—i.e. who does them, how, and when."[20]

Personal assistance services that are based on this concept imply distinguishing features with regard to setting, service delivery method and helping style. Those are: (1) Assistance is provided in the home or private environment of the consumer; (2) Services are provided as a commodity, not on the basis of charity and altruism. The delivery method in general is composed of attendant referral and actual assistance and involves at least three parties: the consumer, the (referral) center and the attendant; (3) The consumer, not the provider, directs the provision of personal assistance; and (4) health maintenance and medical care, if at all, play only a subordinate role. If necessary, those tasks, as any other task of personal assistance, are directed by the consumer.[21]

As a self-help movement, the independent living (IL) movement began to set up its own Centers for Independent Living (CIL). The famous first one was founded in 1972 in Berkeley, by disabled students of the University of California who had to find a way of organizing personal assistance services if they wanted to live in the community.[22]

Managed primarily by disabled staff members, CIL Berkeley now offers a wide range of services to disabled members of the community. Among them: attendant referral, transportation, advocacy services, training in IL skills and health maintenance, housing referral, wheelchair repair, and peer counselling.[23] Unlike other Centers, CIL Berkeley so far has not offered a residential program.

On the East Coast, ECIL, the Center of Independent Living in Boston, was opened in 1974. There services focused on the provision of attendant services in cluster apartments, transitional housing service and housing referral.[24]

Transitional housing service is a program for disabled persons who need some training before they can live on their own. For a short period of time, residential services are offered in an ECIL-owned facility, During that time the consumer is introduced to basic IL skills, such as attendant managing, household maintenance and health care training.

Attendant service in connection with cluster apartments differs from other attendant service in so

The models differed according to whether they provide ongoing or transitional service, whether they are residential or non-residential, and whether they provide direct or referral services. The philosophy of IL as a form of self-determination, however, has been uniform.

far that a certain staff is provided for several apartments within one or several nearby buildings. Disabled persons who live in those apartments share this attendant staff by calling on them when assistance is required.

Another CIL which opened in the early seventies was "New Options" in Houston. There the main focus among a wide range of services offered was on transitional housing.[25]

CIL Berkeley, ECIL and "New Options" show that there were different models of Independent Living from the early beginning of the IL movement. The models differed according to whether they provide ongoing or transitional service, whether they are residential or non-residential, and whether they provide direct or referral services.[26] The philosophy of IL as a form of self-determination, however, has been uniform. The variety of services offered grew as CIL's developed and became more established.[27] Yet attendant services remain one of the key services of CIL's.[28] By the end of 1981 about 200 CIL's had emerged throughout the United States.[29]

B. The Swedish Independent Living Movement

Sweden was one of the first countries to adopt the normalization and desegregation principles. In the 30's already, inhome household services for disabled persons (and other groups, such as families with children) were part of the social welfare system. In the 60's Sweden was one of the Scandinavian nations that was internationally recognized for its desegregation policy. For severely disabled persons, however, social services were rare. Therefore, persons who needed more personal assistance than during official working hours available, had to rely on family members or were kept institutionalized.

In response to this shortcoming the "Fokus Foundation" was created by disability organizations[30] in 1968. Its main goal was to realize integrated living for disabled people who needed access to personal home-based assistance for 24 hours a day.[31]

The solution was seen in cluster housing, where, in addition to part time "home helper" services provided by the local governments, a personal assistance staff was on call 24 hours a day, seven days a week.

In response 280 such cluster housing apartments were built in 13 cities of Sweden, the common pattern being that ten to fifteen apartments of one large apartment complex, of 50 or more units, were made accessible and available to disabled persons.[32]

Further political efforts of Swedish disability organizations succeeded in charging the local governments with the responsibility to provide such cluster housing services in 1973. Since that date this approach is referred to as "boenderservice" which has been translated as "housing with service".[33]

By 1985 an additional 720 apartments had been built throughout the country. In order to achieve more integrated living with nondisabled tenants, the number of accessible apartments in one complex has been decreased to in 5-10 units. For reasons of privacy the former concept of common bathing, kitchen, laundry and dining facilities has been abolished.[34]

Despite the achievements of integrated living through "boenderservice", some dissatisfaction of consumers led to what might be called the second generation of the Swedish independent living movement. In 1983, as a result of a seminar on the independent living movement which took place in Stockholm[35], STIL (Stockholm's Independent Living Group) was founded in order to seek more consumer input into Swedish personal assistance services.

Dissatisfaction arouse over several perceived shortcomings of the cluster housing solution as well as the municipal personal assistance service such as: the high turnover among the staff, the frequent changes of workers whom a consumer is exposed to and the limited consumer power in the decision of who is to assist a given tenant.[36] Further conflicts arose because the high professionalism of personal assistance service was seen to have the side effect of paternalism towards the disabled consumer. For instance, assistants who were employed by the local governments, were obliged to report problems they noticed in the apartment of the consumer, such as alcoholism, sickness or lack of technical aids. While this obligatory observation might have prevented emergency situations for some disabled consumers, others felt it was an invasion of their privacy.[37]

In contrast to other Swedish disability organizations, STIL's constituency consists of disabled persons with extensive disabilities who recognized that, unless they take up the issue themselves, the independent living concept will not be implemented for them.

While STIL does not reject cluster housing as one possible option for integrated living, its agenda focusses on consumer input in terms of the independent living concept:

> *"Persons with extensive disabilities, according to STIL, despite their common need of personal assistance are individuals with different personalities and social and economic background who have the same right to find their own way of living as their non-disabled peers. The flexibility implied by this right, STIL members claim, depends on two requirements:*
>
> - *Not linking housing and services into a bundle as in cluster housing*
> - *Municipal, or preferably, central state personal assistance allowances directly paid to the consumers to enable them to purchase the service from whomever they choose."*[38]

Meanwhile, about 20 STIL members founded a cooperative in order to organize their own PAS. Each member hires and trains his/her own assistant and has his/her own account within the cooperative in order to pay them. The municipality performs the needs assessment of each cooperative member and PAS benefits are paid directly into his/her account within the cooperative. The amount of benefit corresponds to the costs of municipal assistance services or "boenderservice". Thus, for Stockholm municipality no additional costs are involved.

The members of the cooperative share administrative costs for such tasks as maintaining an office, public relations work, or workshops on attendant management. They also assist each other in dealing with the municipal administration with respect to needs assessment, etc.

Furthermore, the cooperative entered into negotiations with the "home helpers" union in order to clarify the employment relationship between assistant and consumer. The result of these negotiations is a contract between the cooperative and the union.[39]

C. The West German Independent Living Movement

Disability policy in the former West Germany after World War II has been determined by six large non-governmental welfare organizations[40] and a growing number of parents' organizations with special interest in different categories of disability, such as cerebral palsy, polio, mental disability and thalidomide disabilities.[41]

During the early 70's the first self-help groups of younger disabled people emerged, persons who strongly rejected the traditional attitude and wanted to speak for themselves. Inspired by the Scandinavian and Italian desegregation movements, these groups sought integration into the mainstream of society for all disabled persons regardless of category and severity of disability.

The non-governmental welfare organizations have a long tradition in Germany, officially being acknowledged as bodies of the social welfare system in 1926. They basically provide social services to the needy of all groups across the population. Among a wide variety of services, they own hospitals, institutions, and community-based "Sozialstationen". The latter are a sort of social agency delivering medical and nonmedical inhome support services to families with children, ill or disabled persons and elderly people.[42]

Since they additionally conduct research and work closely together with governmental departments, their influence on disability policy is significant.[43]

The parents' groups constituted themselves as self-help groups providing information and counselling to parents of disabled children.[44] The welfare organizations and the parents' groups have in common that their approach to disability is determined by altruism and charity.

During the early 70's the first self-help groups of younger disabled people emerged, persons who strongly rejected the traditional attitude and wanted to speak for themselves. Inspired by the Scandinavian and Italian desegregation movements, these groups sought integration into the mainstream of society for all disabled persons regardless of category and severity of disability. Besides integrated education and access to public transportation, the main focus was on deinstitutionalization.

At that time hardly any alternative to institutional living existed for disabled persons in need of personal assistance.

"Sozialstationen" services basically provided "meals on wheels" and paramedical inhome treatment through nurses. Those with more needs were left with the "choice" between family support—if available—or institutionalization in one of the large rehabilitation centers, boarding schools for disabled

After a radicalization of the disabled movement during the International Year on Disability in 1981 which brought about a boom of new disability groups, personal assistance centers, known as "Ambulante Hilfsdienste" (AHD) organized by disabled persons and their nondisabled friends spread over the country.

children, or nursing homes. Some disabled and nondisabled members of the emerging disability movement tried to change this situation by organizing 24 hour attendant services.

The first well-known self-help organization providing 24 hour personal assistance services and transportation was founded in Munich 1978 by inhabitants and staff members of "Pfennigparade", at a large institution for disabled persons called VIF (Vereinigung Intergrationsforderung e.V). The group's initial goal was to realize independent living for its disabled members, but very soon the clientele grew. More disabled people moved to Munich due to the lack of daily 24 hour personal assistance services elsewhere in West Germany and arising dissatisfaction over the shortcomings of professionalized services available from "Sozialstationen".

Similar self-help groups were founded in Frankfurt and Cologne. After a radicalization of the disabled movement during the International Year on Disability in 1981[45] which brought about a boom of new disability groups, personal assistance centers, known as "Ambulante Hilfsdienste" (AHD) organized by disabled persons and their nondisabled friends spread over the country.[46]

Unlike "Sozialstationen", the centers' services are not limited with regard to time or assistance tasks such as household maintenance. The principle is that personal assistance services should be provided in all fields of daily living; at home as well as at school or work and during leisure time. Customers are disabled persons of all ages and all kinds of disabilities.[47]

The organization structure of AHD's differs with respect to the range of services provided[48] and service delivery method. Some provide only attendant referral service; most have an additional pool of employed attendants consisting mainly of conscientious objectors between the ages of 18 and 25 who complete their mandatory social service as a substitute for military service.[49]

Others try to implement the independent living concept as developed in the United States, inspired by an international conference on Independent Living which took place in March 1982 in Munich.

All AHD's, however, share a common platform of four principles:

- Because disabled persons are the best experts on their own disabilities they determine their need of personal assistance themselves.
- Assistants shall be lay-workers in order to prevent professional paternalism.
- Except for some basic introductions provided by the centers, attendants are trained directly by the consumer.
- The consumer pays the attendant directly on a fee-for-services basis.[50]

The realization of these principles varies from center to center, and some modifications have been adopted as to personal assistance for persons with cognitive disabilities. However, the platform still functions as a general guideline.

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III. Obstacles to Comparing Social Welfare Programs

A comparison of social programs and associated legislation of the United States, Sweden and the Federal Republic of Germany concerned with personal assistance services (PAS) faces a variety of problems.

In general, every social insurance and social welfare program has its own historical, economic and social background which shapes the values and goals incorporated in each country's system and the relationship between individuals' government and society.

For example, Sweden in not without reason referred to as a "Welfare State". It is a small highly industrialized country, which has not been at war for over 170 years and which during World War II and up to the 70's experienced much better economic growth than other countries. Social welfare policy is committed to assuring all members of society the opportunity to realize their potential for growth and self-fulfillment.[51]

The dominant role of trade associations as well as nongovernmental welfare organizations with more than a hundred years of history is unique to the German history of social welfare. While the rights to welfare and social insurance are constitutionally protected[52], the relationship between government and citizens with regard to social welfare and security is determined by a societal concept of organized self-help with some reluctance to institute strong government control. This led to a system of social welfare and social insurance in which administration is shared between trade and industry associations and welfare organizations on the one hand and government on the other hand.[53] The United States, as already mentioned, is known for its strong civil liberty and rights history but comparatively has a "poor record" with respect to social security and welfare rights. The relationship between (state and federal) government and citizen seems to be much more determined by the "right to be let alone" and the norm of individual self-help[54] than by a right to welfare or social security.[55] Another unique feature in certain U.S. welfare law and programs is the concept of "cooperative federalism", which has been incorporated by the Social Security Act of the 1930's and is based on a shared or joint approach of federal and state government to certain welfare and security issues.[56] As a consequence, unlike Sweden and West Germany, the United States' administrative organization is determined by vertical as well as horizontal divisions of administrative authority.[57]

These basic differences among the three countries have to be kept in mind to enable comparison of their systems of social insurance and welfare programs.

Further difficulties arise when one tries to isolate and compare the systems in terms of a single issue such as Personal Assistance Services (PAS) for persons with disabilities. Here, the danger is even greater of giving a false picture of the situation of the people under consideration.

Furthermore, it should be noted at this point, that the presence or absence of a certain program or procedure might be caused not only by legislative inaction or intention but rather by the existence of other "resources", such as private insurance, or compensation in other legal fields such as torts.

None of the three countries provide a single disability PAS program for all persons regardless of income, status or cause of disability. For this reason it is important to look at the disability benefit system

None of the three countries provide a single disability PAS program for all persons regardless of income, status or cause of disability. For this reason it is important to look at the disability benefit system of each country in a more general way and to ask where PAS has been acknowledged as an important need and how and to what degree this need is being fulfilled.

of each country in a more general way and to ask where PAS has been acknowledged as an important need and how and to what degree this need is being fulfilled. There are different ways in which this issue can be approached. Some countries consider PAS need as part of special living expenses and approach the issue within their income maintenance scheme. Another approach would be to view it as an entirely medical problem, thus delegating the issue to the field of health insurance and medical care.

PAS benefits can be provided in cash or in kind. This will raise the issue of whether inkind or cash benefits are more likely to meet the concept of independent living.

Two more obstacles should be mentioned with regard to a comparison of disability benefits in general and PAS for disabled persons especially.

First, in almost all countries with social security systems and disability law, one finds several definitions of disability. Commonly, definitions relate to the general purpose of the program or legislation in question.[58] Who is considered to be disabled can differ enormously according to the various approaches. For instance, a medical model of definition which looks at certain deviations from the departure point of a non-disabled physical or psychological condition, might provide a long list of identified disabilities derived from a certain standard of scientific knowledge.[59] This list will, however, not be concerned with the actual skills of those persons labelled "disabled".

A contrasting vocational approach to defining disability looks directly at a person's ability to engage in gainful employment. Yet here too, the group of "disabled" persons can be broadened by looking at the ability to work in general and tightened if one looks at one professional activity only. Vice versa, a person might be disabled with respect to most jobs, but be very qualified for one certain job.

Other factors, such as environmental and social attitude can influence a disabled person's functional limitation. For instance a wheelchair user who lives in a community where streets, public buildings and transportation are accessible does not need an assistant in order to overcome steps.

The last factor plays an important role in determining who needs PAS. Accessible housing and transportation, as well as technical aids can greatly diminish the need for PAS.[60] However, even under optimal accessibility conditions, there will always be a need for PAS by some disabled persons.[61]

The thesis will not cover housing and public accommodation policy—including transporation[62]. Rather, the focus shall be on PAS in its purest form, meaning a persons assisting a disabled person in daily living activities.[63]

Since the paradigm for PAS in this thesis is the concept of independent living, each country's system will be scrutinized with respect to personal assistance in all fields of daily living; at home, in school and at work and with regard to all ages.

IV. Personal Assistance Services in Sweden

A. Social Security and Welfare in Sweden

Sweden's social insurance and welfare system is known for covering pretty much the entire population with regard to a wide range of needs. As mentioned earlier, using social welfare aids is not considered as a state of unwelcome dependency but rather as a state of unwelcome dependency but rather as a means for all members of society to realize their potential for growth and self-fulfillment.[64] The basic welfare philosophy rests on the concept of solidarity among all people in Sweden and on the goal that everyone should be entitled to a share of the system on equal conditions.[65]

B. Social Benefits for (Inhome) Personal Assistance Services

The need for personal assistance is acknowledged by both the social insurance and social assistance systems. It is illuminating that from the very beginning, inhome services were not only provided to disabled people but also to parents with children, single mothers and elderly people.[66]

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1. Social Insurance

Social insurance is defined to include national health insurance (medical, dental and parental insurance), and national pension insurance (partial, basic and supplemental insurance), as well as work injury insurance and unemployment insurance.[67]

a. National Health and Pension Insurance

All Swedish residents are registered at a regional insurance office when they reach the age of 16 and are thus eligible for national insurance. Children are covered by their parent's insurance.

(1) Health Care

Health care insurance consists of medical services, sickness benefits and parental insurance.

Medical services include such services as physicians' care, dental treatment, hospital treatment and paramedical treatment (physical therapy, etc.). People who have income loss due to illness, injury or disability are entitled to sickness benefits which—up to a certain ceiling—amount to 90% of the person's regular job income. Parental insurance protects against income loss in connection with childbirth.[68]

In general, the Swedish social insurance system is financed by national and local taxes, fees charged on employers and the self-employed, and interest income or capital withdrawals from various funds.[69] This explains why in principle medical care is free of charge in Sweden although a modest fee is charged for outpatient treatment. The rest of the costs are covered by what is called *"allowance for medical care"*[70] **which cover the various payments to be made in connection with medical care. As a rule these allowances are paid directly by the social insurance office to the health care administration or the individual practitioner in charge of the patient's treatment. Medical allowance also partly covers medical inhome service and rehabilitation for disabled persons, including technical and personal aids such as interpret-**

ing services for deaf persons and inhome health treatment for disabled persons with chronic diseases.

Since health care in Sweden is regarded as being clearly a task of the public sector, these medical services are provided by the local authorities, the county councils.[71] The county councils are responsible for meeting the medical needs of all residents according to the Health and Medical Service Act of 1983.[72] The Act sets general standards for health care: It must be of good quality and meet the needs of population. It must further be based on the patient's right to self-determination and integrity.[73]

Apart from these standards, however, the county councils have vast discretion with respect to organization, scope and personnel of the medical service.

Since health care in Sweden is regarded as being clearly a task of the public sector, these medical services are provided by the local authorities, the county councils.

Another disability-related benefit within the health insurance scheme is provided by the *parental insurance.*

Though its main purpose is to provide benefits in connection with childbirth[74], it also assures benefits to parents who have to abstain from work in order to look after a sick or disabled child for a period of up to 60 days a year.[75]

(2) Pension Insurance

The national pension insurance scheme consists of mainly two types of public pension: (old age) basic pension and supplementary pension (ATP). Both pensions refer to a certain "base amount" according to which the actual payout is computed.[76]

The main difference is that, unlike basic pension, the ATP pension requires that the pensioner had earned income for a certain amount of years. A person who had earned income in excess of the base amount for at least three years, is entitled to-earning-related benefits on top of the basic pension.

The *basic pension* is currently 96% of the base amount for a single person. This amount, however, is not sufficient with respect to daily living costs. Therefore, there is a special benefit for pensioners who receive no or little ATP pension, called *pension supplement*. In 1987 it amounted to 48% of the base amount per annum.[77]

Disabled persons are eligible for this basic pension—in this case called *disability pension*—if they are 16 years or older, have not reached the retirement age of 65 and have a reduced working capacity by at least 50%. A full, two-thirds or half the basic pension may be granted depending on the extent of reduced working capacity.

In addition, there are special benefits available under the basic pension scheme; disability-related needs are covered by *pension supplement, disability allowance* and *childcare allowance.*

Disabled pensioners who have no or little employment record are entitled to receive double pension supplements to compensate for the high living costs their disability entails.[78]

In addition to these income benefits, a disabled person who needs personal assistance qualifies for a disability allowance to supplement the basic pension.

The benefit is designed to give the disabled persons some financial resources for PAS and other disability-related costs.

A person aged 16 or over, who has become disabled before the age of 65 is entitled to this allowance if the following requirements are met. His/her "functional capacity" has to be reduced for at least one year and to the extent that the insured:

- "requires fairly time-consuming help from another person in his everyday life.
- requires continuous help from another person in order to be able to work or study.
- has considerable additional costs in some other way."[79]

Needs assessment is performed by the social insurance office[80].

Although disability allowances are generally linked with eligibility for the basic (disability) pension, it is also payable to disabled workers or students who have a disability that entitles them to disability allowance. In the case of a worker who has such a disability but who can work to such an extent that s/he is ineligible for disability pension, this benefit is called "disablement compensation".[81]

Unlike pension benefits, the disability allowance is not taxable. Institutionalized disabled people, of course, are not entitled to this benefit.[82]

Childcare allowances are paid to parents who take care of their disabled children under 16 years, who need a considerable amount of help or supervision because of their disability. It is equal to a full

or half disability pension under the basic pension scheme[83], plus supplement benefits.

Like disability allowance, this benefit will not be provided to parents of disabled children under 16 years of age if the disabled child resides in an institution.

(3) Work Injury Insurance

This insurance is compulsory and covers gainfully employed workers, self-employed persons and certain types of students. Its main goal is to compensate for lost income and for medical expenses related to illness or injury connected with work or study.

There are three types of benefits under this insurance scheme: (1) benefits equivalent to those provided under health insurance, (2) benefits similar to basic and ATP pension, and (3) unique benefits like death benefits which is an allowance for funeral costs.[84]

Apart from social insurance benefits for personal assistant needs, means-tested PAS are provided by the local governments, according to the Social Service Act of 1982.

2. Social Welfare

Apart from social insurance benefits for personal assistant needs, means-tested PAS are provided by the local governments, according to the Social Service Act of 1982. Like the Health and Medical Service Act this Act takes the form of a goal-oriented law, under which the municipalities are charged with the responsibility to provide different kinds of social services to their population but on the other hand have great discretion to design their programs according to their own needs. According to Section 1 of the Act the overall aim of social service is:

> *"Public social services are to be established on the basis of democracy and solidarity, with a view to promoting economic and social security, equality of life conditions and active participation in the life of the community.*
>
> *With due consideration for the responsibility of the individual for his own social situation and that of others, social services are to be aimed at liberating and developing the innate resources of individuals and groups. ...*
>
> *Social service activities are to be based on respect for the self-determination and privacy of the individual."*[85]

While these goals demonstrate a new direction in social welfare legislation, the present Swedish personal assistance scheme has not yet changed significantly since its beginning in the 30's.

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C. Personal Assistance Services with Respect to Education and Employment

Since 1965 personal assistance is available for disabled children at school age.[86] Tasks offered are personal help with going to the toilet, help with lunch, taking notes, interpreters for deaf children, assistants for children with mental disabilities, etc. Depending on the extent of assistance need, a student might have his/her own assistant or share one with other kids.

The assistants are employed by the school and are free of charge to the students. The costs are shared between local and central government.[87]

A similar program exists at the secondary and university level with the difference that assistants are employed by the community where the university is located. These attendant services are free of charge to the students and are provided in addition to the disability allowance mentioned earlier.[89]

The local governments are reimbursed by the central government which bears the costs.[89]

The Work Environment Act of 1978 now prescribes that the employer has the duty to adapt working conditions to the needs of disabled employees.[90] Employers who hire disabled workers receive subsidies from the State. In the beginning of the employment relationship these subsidies amount to 100% of the employment costs and gradually disappear over the next few years.

A wide range of technical aids are available for disabled workers. A relatively new addition among the list of accommodations is personal assistance for disabled individuals who need practical assistance in a work situation.

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the list of accommodations is personal assistance for disabled individuals who need practical assistance in a work situation. The person assisting may be another employee or someone outside the firm. He or she is employed by the employer who receives reimbursement from the government up to the certain extent.[92] Grants from the National Board of Labor are sometimes also available.

In most districts PAS in form of home helpers is available only during the week and during regular office hours. Service outside this schedule is then only available in the form of medical care from the home medical services administered by the county councils.

D. Personal Assistance Programs: Administration and Structure

Besides the county home health service mentioned earlier, PAS consists mainly of what is called the *"home helper"* or "home samaritan service".[93] A modest fee is charged for the service.[94] Its initial purpose was to serve elderly people and this age group of disabled persons represents still the majority of the clientele.[95]

Home helper services are administered by the municipal social service office located at the district level. Social workers coordinate the service, assess the applicant's need for PAS and assign assistants to consumers.

The number of assistance hours granted varies among districts according to the budget of the provider agency and according to customers' needs. Since no operational guidelines govern the procedure of needs assessment, variations have been noticed among customers with the same apparent needs.[96]

According to the statistics, the average number of hours per person is 3.3 per week, the upper ceiling being 30 to 40 hours a week in rare cases.[97]

In most districts PAS in form of home helpers is available only during the week and during regular office hours. Service outside this schedule is then only available in the form of medical care from the home medical services administered by the county councils.[98] Personal assistance available 24 hours outside institutions is, however, available in cluster housing, described earlier as boenderservice.[99]

The tasks of personal assistance provided by home helper service generally consists of household maintenance, cooking, personal hygiene, help with dressing, errands (bank, post office, etc.) laundry, taking walks and similar assistance.[100] Usually the home helper service is confined to the home of the disabled person.

In addition a few communities have recently started *escort services,* designed to meet the needs of those customers who need help outside their homes while shopping or during leisure time. This service is limited for users with more severe disabilities and only available for a few days a month.[101] It also has to be applied for several days in advance.

Another more recent reform is the *patrol service* offered by some municipalities during night hours and on weekends. The patrol, a staff of usually two helpers, visits consumers on a pre-arranged schedule and helps with going to bed and prepare for the night. They are also on call for emergency situations.

Assistants of the home helper service are employed by the municipality and although most are unionized[102], they are paid the lowest municipal wages[103], due to the fact that the level of professionalization is relatively low[104]. About 80-90% of the assistants are females, usually middle-aged, whose employment background is as housewives. Only 7% worked on a full time basis in 1982. About 14% of all assistants were relatives who are employed by the local government providing assistance to their disabled family member.[105]

While the trend towards full-time employment has increased in the 80's, the numbers of family members gainfully employed as an assistant to their relative has been described as decreasing. An explanation is seen in the demands by the unions for more professionalization and higher salary.[106]

E. Evolution of the Swedish System of Personal Assistance Services

In Sweden the need for personal assistance due to disability is considered in every field of daily living. Both the social insurance system and the welfare scheme entail provisions for PAS.

Personal assistance is clearly separated from medical treatment, a division which supports the IL concept.[107]

In Sweden the need for personal assistance due to disability is considered in every field of daily living. Both the social insurance system and the welfare scheme entail provisions for PAS.

Families with disabled children and older disabled members are supported by provisions within the social insurance system as well as by the municipal welfare system. Thus the Swedish system recognizes that PAS are PAS even if they are provided by family members and that these people deserve to be compensated. It reflects an awareness of the Swedish Government that providing PAS on a voluntary basis through family ties, substantially reduces the family's earning capacity.

One of the most important features of the Swedish PAS system seems to be that disabled persons are encouraged to be gainfully employed, since PAS is available at work and the home helper service does not exclude gainfully employed disabled persons.

One of the most important features of the Swedish PAS system seems to be that disabled persons are encouraged to be gainfully employed, since PAS is available at work and the home helper service does not exclude gainfully employed disabled persons.

However, the choices for persons with severe disabilities are still very limited. Neither the disability allowance nor the PAS provided by the communities cover the needs of those disabled persons who cannot cope with a couple of hours assistance a week. The fact that public help is mainly unavailable during weekends and outside regular office hours has significant implications for persons with more severe disabilities. They are left with the choice between family support, boenderservice and institutions. In this regard it may be interesting to note that among the group of elderly disabled persons who have moved into an institution, the average amount of assistance they received shortly before, was three hours a day.[108] Thus, it seems that most PAS are not designed to function as a true alternative to institutionalization, but rather as a means to delay the date of institutionalization.

Another problem with regard to the independent living concept is the organization of the home helper service. In contrast to the principles of "respect for self-determination" and "privacy of the individual" as laid down in the Social Service Act of 1982, consumers have no influence on the decision as to who is going to be their assistant, and they are not in the position of an employer towards their attendants. The high turnover rate among attendants is one of the most frequent complaints of disabled consumers.

Currently, Swedish social service programs are characterized by a trend towards professionalism, promoted by the unions who have interest in improving the status and salary of personal assistant workers.[109] While some disability organizations support the union's demand for more professionalization of home helper services in hope of a better service quality, others view this trend with more skepticism. As described above, from the IL perspective, a high degree of professionalization of PAS is fraught with the danger of paternalism.

Apart from their agreement with the demand for an increase of assistant wages, members of STIL see this as an obstacle to more consumer directed personal assistance.[110] The term "home samaritans", frequently used for home helpers, is seen as an indication of such paternalism. Another indication of paternalism is seen in some of the new experiments undertaken by some of the communities in recent years. For example, the introduction of assistant teams, which in Stockholm consists of groups of four to five. They are provided with an apartment by the city in order to have a place for meetings, meals and assigning the daily tasks to each other at a morning meeting. The underlying concept is to improve their working conditions. Some users are dissatisfied with this solution, because, apart from having no input into the decision who is going to perform their personal assistance, they fear that details about their private lives will be divulged.[111]

Another experiment of professionalization which has been criticized as paternalistic is that more and more social service offices charge their assistant workers with the task to "activate", consumers, meaning, to motivate them to do as much as possible on their own. For instance the worker will dust off the upper corner of a picture on a wall and will "activate" the consumer to do the part which can be reached from the wheelchair level.[112] Users, who might be able to perform these tasks but need more time and energy than a non-disabled person, have criticized that this deprives them of the choice on how to spend their energy. Time and energy they might rather want to use for employment, for example.

A female consumer of boenderservice expressed her dilemma this way: "It is only after I moved to boenderservice that I no longer have control over which men enter my bedroom."

A third example of these kinds of experiments is a decision by the Stockholm social service office prohibiting assistants from buying alcoholic beverages for their customers.[113]

Although in some cases those experiments might be sound, they give reason to believe that the criticism against professionalization of Swedish PAS is justified.

In this respect Sweden's home helper service does not meet the IL concept of consumer directed personal assistance. Furthermore, it does not comply with the IL principles laid down in the Social Service Act of 1982. While one might argue that legal reforms always require a couple of years before changes are implemented, the new trend of professionalization with the PAS seem to take the opposite direction.

Both, law and administration offer few choices for persons with personal assistance needs that exceed the average amount of service. The disability allowance might be efficient for the lower fees of home helper service, but will not cover the costs of several hours daily assistance.[114]

Clearly there is a lack of consumer involvement—as a group and as individuals—in Swedish PAS. The area where this lack is felt most is in the assignment of assistants and the high turnover rates among staff members.[115]

Since PAS involves intimate assistance and close social relationship during a large part of the service, fundamental privacy interests of the consumer are involved. A Female consumer of boenderservice expressed her dilemma this way: "It is only after I moved to boenderservice that I no longer have control over which men enter my bedroom."[116]

V. Personal Assistance Services in the United States

Unlike Sweden, the United States does not have a comprehensive and strongly centralized social security and welfare system. Rather, viewed by an outsider, the U.S. appears to have a labyrinth of diverse programs instead of a system. Private and public insurance, self help groups, private and public services, federal, state and community programs and more constitute what is called the "social net" of the United States.

As described in Chapter I., the independent living movement from the beginning has been concerned with civil rights and social benefits. Therefore, PAS in the United States have to be viewed in this context. While the main focus will be on social security and welfare law, a brief insight into antidiscrimination law relating to disability will also be given.

A. Antidiscrimination Law and the Right to the Least Restrictive Environment

In the early 1970's when disabled persons sought protections similar to those the civil rights movement had secured for racial and ethnic minorities and women, Congress enacted a wide array of antidiscrimination laws related to disability.[117] Besides prohibiting discrimination, most of these laws also provide for and create programs of services for disabled persons. Congress considered both nondiscrimination as well as the provision of various services essential for equal opportunity and full participation of disabled people in society.

In the early 1970's when disabled persons sought protections similar to those the civil rights movement had secured for racial and ethnic minorities and women, Congress enacted a wide array of antidiscrimination laws related to disability.

Thus, for instance, *The Developmental Disabilities Assistance and Bill of Rights Act*[118] was enacted. It deals with Federal- State grant programs to assist and encourage States to improve care and training for developmentally disabled citizens.[119] In addition to mandating delivery of various services, the act also contains a "Bill of Rights" designed to protect and advocate the rights of these developmentally disabled children and adults. With respect to full participation in society, the declaration that disabled persons have "a right to appropriate treatment, services and habilitation" that "maximize the developmental potential of the person...(and are) provided in the setting that is least restrictive of the person's personal liberty"[120] is essential.

In several other state and federal statutes the concept of "least restrictive environment" has been incorporated, such as the *Federal Education for All Handicapped Children Act* of 1975[121] concerned with equal educational opportunities for disabled children, which requires States to assure that disabled children are educated in the least restrictive environment. The phrase "least restrictive environment" has been defined as a setting in which disabled children are educated with nondisabled children to the maximum extent possible.[122]

An example of a state statute is *The Lanterman-Petris-Short (LPS) Act* passed by the California Legislature in 1967, designed to define and protect the rights of people with mental disabilities, later amended to more broadly address developmentally disabled people. It prohibits discrimination and provides "(A) right to treatment and habilitative services...[under] least restrictive conditions".[123] Today most States have enacted similar Statutes and "least restrictive environment" has become a catch phrase for community-based facilities among disability advocates. Several courts interpreted the "least restrictive environment" doctrine as a civil right for

institutionalized disabled persons to receive community-based assistance services[124] based on statutory or constitutional provisions.

The optimism created by those early court decisions, however, has been eroded by two Supreme Court decisions and the subsequent prevailing climate of judicial restraint and deference to professional judgement.

While deinstitutionalization led to a partial closure of institutions and legislative programmatic commitments to deinstitutionalization, it was not accompanied by a corresponding development of adequate community services which would facilitate independent living situations for the (mentally) disabled.

In *Pennhurst I*[125] the Court held that the Bill of Rights of the DDA does not establish a substantive right to community-based treatment for developmentally disabled persons. It interpreted the Bill of Rights sections as a mere congressional preference for deinstitutionalization. Similarly the Court in *Youngberg v. Romeo*[126] held that since in general "the state is under no constitutional duty to provide substantive services for those within its borders"[127], an institutionalized disabled person has only narrow constitutional rights to "minimal adequate training".[128] The interpretation of what constituted adequate training was treated with judicial deference and left to professional expertise.

Since these decisions, few courts have found that community-based services were required as a matter of law. Only if there was professional consensus that institutional confinement was inappropriate, did courts order deinstitutionalized treatment.[129] Other courts found no basis at all for a constitutional right to a least restrictive environment.[130] With regard to statutory "least restrictive alternative" provisions, increasingly courts held, similar to the Supreme Court's *Pennhurst I* decision, that they do not contain enforceable rights to community-based assistance services.[131]

While deinstitutionalization led to a partial closure of institutions and legislative programmatic commitments to deinstitutionalization, it was not accompanied by a corresponding development of adequate community services which would facilitate independent living situations for the (mentally) disabled.[132]

A similar process took place with the Centers for Independent Living, mentioned earlier. These centers were legally acknowledged by Congress in the 1978 Amendment of the Rehabilitation Act.[133] Again, with this statute, Congress passed a programmatic commitment to the principles of normalization and independent living for disabled Americans. With Title VIIb of the Rehabilitation Act of 1973[134], Congress established a four-part program for more severely disabled persons. Part A of Title VII of the Rehabilitation Act authorized payments for independent living services that are provided under appropriate State plans. Part B authorized a grant program for the establishment and operation of Independent Living Centers that provide among several other PAS. Part C established funds for independent living services for elderly, blind individuals. The basic funds authorized under Part B of Title VII were helpful in setting up about 160 Independent Living Centers in the U.S.[135]

However, the Rehabilitation Act has never been the main federal funding source for PAS, even though Title VIIb is one of the few federal statutory provisions that mentions attendant services explicitly as one of the services to be provided. One explanation is that the funding has always been minuscule in comparison to federal money that has been used for institutionalized care.[136] However, the services that were to be provided under Part A of the program were funded for the first time only in 1984, more than six years after it was enacted, the amount appropriated being $5 million.[137]

B. Social Security and Welfare Law in the United States

U.S. social security and welfare law in the modern sense is relatively young. It begins with the enactment of the Social Security Act in 1935, when the Depression made poverty a national problem, and led to the New Deal era. Since then the emphasis of America's social security policy has been on income maintenance through programs similar to those carried out in European countries—OSDI (Old Age Survivors and Disability Insurance), Unemployment Insurance, Workers' Compensation—or else means-tested programs like AFDC (Aid to Families with Dependent Children). All these programs are designed to substitute benefits for lost income.

Health and social services have long been considered outside the public domain. Thus, there is no centralized national health insurance with mandatory coverage or a strong social service system with respect to child care, or income support services. Nevertheless 95% of the population is said to be covered to some extent by public or private health

insurance programs.[138] The health programs and social services are largely in the hands of the private sector.[139]

There are, however, two large public programs—called "Medicare" and "Medicaid"—providing medical services to a considerable portion of the population. Medicare[140] is a federal program providing health insurance for persons over 65 years and disabled people who are eligible for retirement benefits or disability benefits whereas Medicaid[141] is a means-tested joint federal-state program designed to provide medical assistance and services to the needy.[142]

1. Income Maintenance Programs For Disabled Americans

The concentration on income maintenance as the major focus of public social security and welfare programs has been a determining factor for the development of disability policy in the United States as well. In general, the programs dealing with disability provide income substitutes but do not cover disability-related expenses, except those of the most basic medical sort.

a. Worker's Compensation

Worker's compensation, one of the first forms of social insurance in the United States[143] provides cash benefits and medical care when workers are injured in connection with their job. The benefits are usually calculated as a percentage of weekly earnings at the time of accident or death.[144] While a number of state programs take marital status and the number of dependent children into account, and in most laws additional benefits are allowed for compensation of "disfigurement", only a few programs provide benefits for necessary attendant services.[145]

b. Social Security Disability Benefits

Social Security Disability Benefits (SSDI) provided for by the federal Disability Insurance (part of OSDI, supra) are similarly related to lost earning capacity. The amount of a disabled worker's benefit is computed on the basis of his/her working record. The benefits include spouse's benefits, child's and survivor's benefits but do not afford disability allowances for needed personal assistance services.[146]

c. Federal Supplement Security Income

The same is true for another major disability program, the Federal Supplemental Security Income (SSI).[147] SSI provides a minimum guaranteed income for disabled persons under 65 who meet a means test, have had little or no working experience and are unable to engage in substantial gainful activity. As of 1986, the amount of monthly payments were up to a maximum of $325 to $488 for a qualifying disabled person with a spouse. The average payment in 1986 was estimated to be $199.[148] Although all but two States supplement these federal payments[149] and the States have wide discretion in their optional supplementation level. In no state is SSI a significant funding source for disability-related personal assistance needs.[150]

The concentration on income maintenance as the major focus of public social security and welfare programs has been a determining factor for the development of disability policy in the United States as well.

d. Veteran's Compensation

The only major federal program providing for personal assistance services in addition to income maintenance is the Veteran's Compensation Program for Service-Connected Disabilities.[151] As in most countries with social security systems, this group of disabled persons has a privileged status and those qualifying are entitled to a wide array of programs and benefits. In addition to monthly cash payments as compensation for a disability resulting from military duty, veterans in the United States receive an "Aid and Attendance Allowance" if they are considered severely disabled. Compensation payments in 1986 ranged from $66 a month for a 10%-disability to $1,295 a month for a total disability.[152] However, compensation and allowance together may not exceed a maximum of $3,697 a month.[153] In 1984 the veterans' administration paid 8,493 persons $101,036,520 in "Aid and Attendance Allowances". Some 6,860 individuals received an amount of $906 per month. The remaining 1,633 people, who were considered being at risk of institutionalization, received $1,350 per month.[154]

While Veteran's Compensation enables most beneficiaries to live at home and pay their own attendants, the situation is different for the majority of the disabled population who have to rely on SSDI or SSI money.

In establishing SSDI and SSI the federal government acknowledged its responsibility to provide for the basic living needs of disabled persons. The programs are not, however, designed to allow disabled persons to live independently.

2. Federal Legislation Providing Funding Sources for Personal Assistance Services

In addition to the Veterans' Aid and Attendance Allowance, there are currently four major Federal programs which fund personal assistance services in a broader sense: 1) *Title XVIII (Medicare)* of the Social Security Act; 2) *Title XIX (Medicaid)* of the Social Security Act; 3) *Title XX (Social Service Block Grant)* of the Social Security Act, and 4) *Title III of the Older American Act.*[155] In addition, there are several state or local programs providing funds for PAS. In general, states utilize federal funding for these programs, too.[156]

In establishing SSDI and SSI the federal government acknowledged its responsibility to provide for the basic living needs of disabled persons. The programs are not, however, designed to allow disabled persons to live independently.

a. Medicare (Title XVIII of the Social Security Act)

This health insurance for retired and disabled persons who have been part of the work force includes two related contributory health insurance plans: Hospital insurance (HI) and a voluntary program of supplementary medical insurance (SMI). Both insurance plans provide for home health services only if the disabled person is homebound, is under the supervision of a physician, and only if the service is furnished by a home health agency, or subcontractors of a home health agency who work according to a plan established and periodically reviewed by a physician.[157]

Furnished services are subject to the condition that they are confined to the residence of the recipient.[158] In addition, the medical character of these home services is emphasized by specific exclusions.

As a general principle, any service that would not be covered if furnished to a hospitalized patient is excluded from coverage. Explicitly food service arrangements (such as meals-on-wheels), household maintenance services and transportation services are excluded.[159] Services which are not considered reasonable and necessary for the treatment of illness or injury are not covered by Medicare and form another general exception.[160] If home health services are provided by "immediate" family members (spouse, child, brother, sister, brother-in-law, etc.), there will be no reimbursement by the insurance.[161]

Thus, Medicare home health services operate according to a strict medical model. Many of the above mentioned tasks of PAS are excluded and, since the physician and skilled nursing agency are vested with broad authority, there is no real avenue for consumer involvement.

Although since 1981 home health visits are not limited to a specific number of visits per year, Medicare has not become a major source for (long term) home health care. In 1982 about 1,171,000 people (93% of whom were aged) received home health services under Medicare. The average number of visits were 26.3 in that year.[162]

b. Medicaid and Medicaid Waivers

(1) Medicaid (Title XIX of the Social Security Act)

Medicaid was created as a federal-state means-tested entitlement program to provide medical assistance to the poor. While the federal government mandates that certain services be offered—among them in-home-support services—states administer the program and have wide discretion with respect to income eligibility levels, scope and duration of benefits, the availability of services, delivery and reimbursement methods, etc.[163]

In most states eligibility for Medicaid is linked to existing cash welfare programs, such as Aid to Families with Dependent Children (AFDC) and Supplementary Security Income (SSI). Some states have less restrictive eligibility criteria.[164]

The discretionary aspect of laws governing Medicaid quickly led to considerable variations among the states, which is still evident today. As a consequence, Medicaid is not a uniform national program but different state programs with wide variations and only some common elements. The program is financed jointly by federal and state funds.

The largest portion of Medicaid funds go to hospital, nursing home and institutional services such as Intermediate Care Facilities (ICF) for mentally disabled persons, Skilled Nursing Facilities (SNF), etc.[165]

Medicaid Inhome services are characterized by the medical model, but the strings are much looser than under Medicare regulations. According to Medicaid law, services must be prescribed by a physician as part of a written treatment plan. They can be provided as home health aid service by a certified home health agency or as personal care service provided by 1) "an individual who is: qualified to provide the service; 2) supervised by a registered nurse; and 3) not a member of the recipient's family"[166].

Some states and cities have found innovative ways to work within this medical model and still involve consumer control. In Denver, New York City and Boston several Centers for Independent Living have been designated home health agencies, who allow their consumers to hire and train their assistants.

Some states and cities have found innovative ways to work within this medical model and still involve consumer control. In Denver, New York City and Boston several Centers for Independent Living have been designated home health agencies, who allow their consumers to hire and train their assistants. Other areas loosen the supervision requirement by having a nurse do an evaluation every three or six months.[167]

Federal funding for Medicaid is open-ended. States are reimbursed by the federal government for the cost of providing services to eligible beneficiaries. Each state's financial participation formula is established based on its per-capita income. States in turn reimburse providers in the private sector through third party vendor payment.[168] Thus, in most cases, disabled persons receiving in-home services under Medicaid do not have financial control over the services they receive. The providers have more incentive to satisfy the state's interests than those of the consumer. In those areas, however, where Independent Living Programs have been designated home health agencies, some centers pay the assistant's wages directly to the consumer who then pays his/her assistant.[169]

(2) Medicaid Waivers (Section 2176 of the Omnibus Budget Reconciliation Act of 1981)

In 1981 Congress paved the way for pilot activities in the field of community-based service in order to decrease the costs for institutional services. By enacting Section 2176, the Home and Community-Based Services Medicaid Waiver Provision of the Omnibus Budget Reconciliation Act[170], Congress created an incentive for states to finance community-based services for people who otherwise would run the risk of being institutionalized. States can apply for a waiver of the Medicaid rules in order to deliver a variety of new services—including PAS—for a narrowly defined population group, and with a more liberal eligibility formula.[171]

While many states have applied for such waivers and a great number of demonstration projects have been established, the potential of the Medicaid waiver program is limited by the federal requirement that the new services be no more expensive than institutional care. Furthermore, waiver grants are limited to a period of three years.[172]

Responding to pressure, Congress has changed the rule not to spend on any individual more than the average cost of a nursing home. Disability advocates successfully argued that such a regulation discriminates against persons with extensive disabilities, because most of the people in nursing homes are older people with fewer service needs. By enacting the Consolidated Budget Reconciliation Act in 1985 Congress established a new two-tiered limit for people with different levels of service needs. On the other hand, however, it has been reported that waivers for more comprehensive community-based services rarely receive federal approval anymore.[173]

Congress created an incentive for states to finance community-based services for people who otherwise would run the risk of being institutionalized. States can apply for a waiver of the Medicaid rules in order to deliver a variety of new services—including PAS—for a narrowly defined population group, and with a more liberal eligibility formula.

c. Social Service Block Grant (formerly Title XX)

Title XX of the Social Security Act[174] was a federal grant program for states' social service programs in different areas, one of which was in-home support services for people at risk of institutionalization. In 1981 it was converted into a block grant in order to give states more latitude in using the funds. Under SSBG regulations states have wide discretion with respect to what kind of services be established and determining eligibility requirements. Most states provide some sort of attendant services using SSBG funds in combination with Medicaid funds for "personal care".[175] But with the exception of California[176] most states do provide only limited attendant services with SSBG money. This is a result of the fact that the funding is not open-ended and the level has been raised only slightly—from $2.57 billion in 1976 to $2.7 billion for 1984, 1985 and 1986.[177]

The program is administered by state and county departments with social workers doing the needs assessment, evaluation, etc. Medical personnel play no role in this program.[178] Thus, the major advantage

of SSBG funding over Medicaid and Medicare is that services are not tied to a medical model.

d. Title III of the Older American Act

With the Older American Act, Congress enacted a social welfare program for aged Americans which comprises a wide array of social and medical services.

Title III of the act is designed to offer personal assistance services by either augmenting existing ones or creating new attendant services. Unlike other welfare programs—like SSBG and Medicaid—Title III is not a means tested program. However, since there is a federal ceiling for funding, local Area Agencies on Aging are encouraged by federal regulations to address low-income people over 60 years old.

States meet federal funding requirements when they can prove that they spend a portion of the funding on special services, like attendant services, or that these services are already available through some other sources. Thus, in general, states combine Title III money with SSGB and Medicaid funding. Unlike SSBG or Medicaid, Title III in addition provides for meals-on-wheels services. Another advantage of this program is that it actually includes services for older persons with all types of disabilities. Thus the service offers attendants, readers, interpreters and companions.[179]

C. Personal Assistance with Respect to Education and Employment

1. Personal Assistance Services at School

Education in the United States is primarily the responsibility of states and local communities. For this reason there is no significant federal program on disability-related services for students. There are, however, two federal laws which have some influence in this area.

Section 504 of the Rehabilitation Act and the related regulations[180] prohibit disability-based discrimination in any program supported by federal funds. Since every state accepts federal money for its education programs, every state is thus prohibited from discriminating against disabled students. The regulations issued to implement Section 504 require fund recipients to undertake "reasonable accommodations" in order to eliminate discrimination.[181]

Under the Education for All Handicapped Children Act (EHA), states that receive federal aid have to assure the provision of "free, appropriate, public education" to all disabled children in the least restrictive environment. If necessary, disabled children must be provided with "special education and related services" at no cost to the parents.[182]

Both phrases "reasonable accommodations" and "related services" embody the same concept. Individualization of opportunities and antidiscrimination efforts for disabled students are not possible without some modifications. Adjustments and supportive services in addition to an educational setting designed to meet nondisabled individuals' needs are required. More commonly, these doctrines have been applied to the need for technical aid, occupational therapy, school health services and transportation.[183] Some personal assistance services, however, have been acknowledged under these laws; such as interpreters for sign language.[184]

Except for a few states such as Massachusetts and Ohio, which have established attendant services for disabled employees, there are few special PAS programs for disabled persons at work.

In passing these laws, Congress recognized that accommodations and related services might involve some costs and established limited programs to help bear them. Section 302 of the Rehabilitation Act, for example, authorizes grants to state units to provide technical and personal assistance (such as interpreters for sign language) in order to comply with Section 504.[185] It has also has been reported that section 110 of the Rehabilitation Act provides some funds for attendant services for vocational rehabilitation clients, which can be used if other sources are unavailable.[186]

With PL 98-199 (Post-secondary Education Program for Handicapped Persons) Congress authorized demonstration grant monies to support interpreting, reading, note taking, tutoring, counseling and related services for post-secondary disabled students. Twenty-one projects were supported with these grants in 1984, while priority was given to four regional programs for deaf students.[187]

2. Personal Assistance Services at Work

Except for a few states such as Massachusetts and Ohio, which have established attendant services for disabled employees[188], there are few special PA-programs for disabled persons at work.

Section 504 of the Rehabilitation Act does of course apply to employers receiving federal funds. Similar, more far reaching provisions exist for federal contractors (Section 503) and the federal government itself (Section 501), both of which are subject to affirmative action duties.

However, the obligation to provide to reasonable accommodation is not unlimited. More than in the area of education—which is considered to be a quasi fundamental right[189]—extensive costs may be used as an argument to escape this duty in the context of employment.[190] Furthermore, the large number of employers who do not receive any kind of federal money are not prohibited from discriminating against disabled workers.

Disabled persons who want to get into the work force, thus, have difficulties finding and carrying out a job if they need PAS to do so.

A national survey on PAS programs in the U.S. conducted under supervision of the World Institute on Disability (WID) reports that only 16 programs (10% of all the programs identified) are aimed at allowing recipients to work, or emphasize work as a goal, while still providing PAS.

Most PAS programs and funding sources are not available to persons with income above the poverty level, which in 1986 was $5,272 a year for a single person[191]. A national survey on PAS programs in the U.S. conducted under supervision of the World Institute on Disability (WID) reports that only 16 programs (10% of all the programs identified) are aimed at allowing recipients to work, or emphasize work as a goal, while still providing PAS.

D. Personal Assistance Programs: Administration and Structure

Personal assistance programs in the United States vary widely from state to state. The scope of services provided depends on which funds are utilized, whether the personal assistance is furnished by private or public providers, which population group of disabled people is addressed, etc.

A national survey of personal assistance programs was conducted by WID in 1985/1986. Since it is presently the only national report on PAS in the United States it will be used as a basis for a description of PA programs. The survey identified 173 PAS programs in the United States, of which 154 could be included in the results of the program.[192] For various reasons, however, programs exclusively for people with mental disabilities and/or people with intellectual disabilities were excluded from the survey.[193]

1. Funding Sources and Dissemination.

The survey shows that currently each state has developed some sort of PAS program: on the average there are about three programs per state.[194] While more than a third of the programs are funded by Medicaid (including Medicaid Waivers), somewhat less than a quarter are funded by SSBG monies.[195]

Title III of the Older American Act is the sole federal funding source for 10% of the programs and Title VIIB of the Rehabilitation Act funds only 0.6% of the programs. On the other hand 22% of the programs are financed entirely by state or local monies.[196] Only 12% of the programs were reported to function on a combination of federal sources.[197] Thus, the major funding sources for PA programs are Medicaid, SSBG and state or local funds. Federal funds accounted for 52% of the expenditure on PAS.[198]

2. Goals, Administration, and Structure

Most programs (45%) are administered by state agencies with jurisdiction over social, health and welfare affairs. Others are administered by the State Agencies on Aging (27%), medical assistance or health departments (17%) and a few are administered directly by Independent Living Centers (in Maine, Nevada, North Carolina, and South Dakota).[199]

While almost all programs are directed at preventing institutionalization, only 10% (16 programs) are aimed at allowing their consumers to work[200], although 72% of the programs serve disabled consumers of working age.[201]

Eligibility for services varies from program to program, based on such factors as age, income, disability type and employment status. Most programs (88%) serve older persons over 60 or 65 years old. Only 41% of the programs serve consumers of all ages with children being the most underserved consumer group. (41%)[202] More than half of the programs (58%) serve consumers of all types of disability, while 10% serve physically disabled individuals exclusively.[203]

Commonly, programs render services to poor persons only. While 50% of the programs either utilize the poverty level as an income limit or link eligibility with entitlement programs (such as SSI, SSDI or Medicaid, whose income eligibility limits are near or below the poverty level), only 23% of the programs accept consumers with income above twice the poverty-level.[204]

In addition, other eligibility criteria are: risk of institutionalization (57%), physician's order (42%), family help unavailable (22%) and other factors.

The scope of tasks included mostly personal services such as bathing, dressing, hygiene and grooming, and household maintenance and related services. The survey shows, however, that help with catheter

management or injections and medication as well as interpreters and readers are less available.[205]

Although more than half of the programs are reported to have some sort of respite service, many program rules require that providers be employees of home health agencies which provide services only from 9 to 5 on weekdays. Thus only 65% of the programs provide services which are available 24 hours a day. Another 12% of the programs offer services earlier than 9 a.m. or later than 5 p.m. but fewer than 24 hours a day.[206] Since many providers are private agencies, often free-market rules determine the availability of services. In less populous areas with little competition, the tendency is that providers restrict the service to regular working hours.[207]

The overview on federal funding sources for PAS shows that there is no comprehensive federal policy on community-based PAS. A labyrinth of funding sources exist, most of which perpetuate a medical approach to attendant services. Consequently, the major funding sources, such as Medicaid, overemphasize institutional and acute care.

Only 28% of the surveyed programs do not have a service ceiling with respect to hours of services available to one consumer.[208] Thus, most of the programs do not offer 24 hour services. Hour ceilings range from 3 to 67 per week, with an average of 29 hours.[209]

There are three models of delivery methods, with attendants divided into three groups: (1) Individual providers (IP), (2) those who work for contract agencies (contract-model), and (3) those who work for county or municipal governments (county-model).[210]

Most commonly, programs utilize the contract model (78%); 50% of the programs are reported to use the IP-model and only 28% use government employees.[211] Many programs, however, use more than one provider model. These models differ according to consumer involvement and wage or reimbursement rate. According to WID's survey, the IP model allows the most consumer involvement in terms of control over schedule, choice of the assistant and which tasks are furnished at what time.[212] However, consumers must have the ability to manage their own attendants, and IP attendants are commonly paid at or very close to minimum wage. The average hourly wage at the time of the survey was $3.74.[213]

Many IP attendants also do not receive any benefits. In contrast, attendants of the county-model have the highest pay and benefits, with an average hourly wage of $4.77,[214] but the model is least open to the concept of independent living and consumer control. These programs rarely allow consumers to train, hire and fire, or pay their assistants.[215]

Contract agency workers are reported to receive an average hourly pay of $4.71 but far fewer benefits than government employees.[216] Most of the workers are home health aides or homemakers of a registered home health agency, while IP workers may be licensed practical nurses, as well as relatives[217] or students.

Government workers are used as PA providers only when there is no contract provider. WID expects their number to decline owing to current federal policies which encourage private enterprise to take over government service.[218]

E. Evaluation of Personal Assistance Services in the United States

The overview on federal funding sources for PAS shows that there is no comprehensive federal policy on community-based PAS. A labyrinth of funding sources exist, most of which perpetuate a medical approach to attendant services. Consequently, the major funding sources, such as Medicaid, overemphasize institutional and acute care.[219]

PA programs that exist are funded by a wide variety of federal and non-federal funds with wide discrepancies among the states with respect to their service capacity. Some states have developed their own very comprehensive attendant service programs, such as California's In home Supportive Service Program[220]. Others do not consider it a policy issue at all. In addition, programs differ according to eligibility criteria. The WID survey shows that 59% of the programs exclude certain age groups, 44% exclude certain types of disabilities and 50% of the programs do not serve people with income above the poverty level.[221]

Another shortcoming is that many programs do not allow family members to be paid attendants.

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The separation of the areas of funding, administration and organization of the programs, led to a diverse array of PA programs. This makes it difficult to analyze who directs PAS policy in the United States. Some programs are financed and administered by the federal government, some are financed federally or jointly, but administered by the states and others are entirely state or local programs. In each variation the private sector is involved as well, and many programs actually are financed by several funding sources.

Delivery model, the scope of services rendered, or the population group served, thus depend on a mixture of these factors: funding source, administration, delivery agency and more.

This interplay of federal and state policy or private and public sector allowed innovative models of PAS to be established. At the same time, however, it seems to prevent the development of a comprehensive national policy which has the capacity to address a "national problem".[222]

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VI. Personal Assistance Services in West Germany

The German social security system dates back over a hundred years. It is similar to Sweden's system, in that it is equally comprehensive. It covers nearly the entire population. But unlike Sweden's system, the German system is not entirely tax-based. And although most of the laws governing the system are federal, the system itself is not administered by centralized government agencies.

The German social security system dates back over a hundred years. It is similar to Sweden's system, in that it is equally comprehensive.

A. Social Security and Welfare in West Germany

West Germany's social "net" can be split into three main categories: (1) The social insurance system, which is compulsory and based on contributions, entails (a) health insurance; (b) accident insurance (similar to Worker's Compensation in the United States) for work-related injuries; (c) the retirement and disability-insurance; and (d) unemployment insurance. (2) The second system is the social maintenance system with compensation benefits for personal injury and the like. It is financed by federal (tax)-funds and covers a variety of benefits (health care, pensions etc.) for victims of war, military service, crime, vaccination victims, etc. (3) Thirdly, the welfare system is a means-tested program for the poor, which is similar to General Assistance in the United States, but which is available to needy people with income below the poverty line and provides for a variety of cash and in kind benefits (such as rent, subsistence grants, health care, but also categorical benefits such as assistance to disabled persons, pregnant women, etc.). It is financed by the Länder[223] with some additional federal grants.[224]

The *insurance scheme* (1), with its various social insurance, is run by insurance bodies which came into being in the course of historical development. When social insurance was made mandatory, already-existing self-help arrangements for certain professions were incorporated into the system.[225]

Thus the insurance funds are independently run by representatives of the insured members and employers. Since these bodies perform governmental functions, they have some sort of semi-governmental agency status. Their umbrella organization fulfills a coordinating role and has great influence on regulations and legislation in this area of social security law.[226]

The *maintenance system* (2) is administered by federal and Länder agencies and the *welfare program* (3) is administered by Länder and county agencies. The various welfare organizations mentioned earlier, often function as contract agencies for a variety of social services provided for under social insurance, social maintenance or social welfare systems.

Although the need for personal assistance owing to disability has never been acknowledged as a risk which must be covered by social insurance (as is the case with illness, work-related injuries, unemployment or war damages-each of the three categories makes some provisions for PAS.

B. Benefits for (In home) Personal Assistance

West German law clearly distinguishes between health care and attendant care (personal assistance). Both services are furnished on an at-home basis and at hospitals or other institutions. For the purpose of comparing West Germany with Sweden and the United States, health care as well as personal assistance services will be mentioned in so far as they are furnished outside institutions.

West German law clearly distinguishes between health care and attendant care (personal assistance). Both services are furnished on an at-home basis and at hospitals or other institutions. For the purpose of comparing West Germany with Sweden and the United States, health care as well as personal assistance services will be mentioned in so far as they are furnished outside institutions.

1. Social Insurance

a. Retirement- and Disability Insurance

Retirement- and Disability Insurance mainly provides for lost income in case of disability (semi-disability pension and total disability pension) and old age (in general at age 65). The pension is based on a working record and no special allowances for disability related needs are provided. In addition to pension benefits for the insured, as well as for spouse, child and survivors, Retirement and Disability Insurance provides for medical and vocational rehabilitation benefits.[227] These benefits do not cover any sort of personal assistance services, however.

b. Health Insurance

Health Insurance provides for various benefits related to health care. Among them, in home health services are provided, if necessary, for medical treatment, or to prevent hospitalization. They must be prescribed by a physician and generally be furnished by a registered nurse or a health professional.

Personal assistance services, such as feeding, dressing, hygienic tasks, are covered only as far as they are closely connected with medical treatment. But in general these services are not covered by health insurance since they are considered non-health related services.[228]

Responding to a rising need for personal assistance services, however, the legislators amended limited personal assistance benefits to Health Insurance recently. According to the Health Reform Act of 1988[229] some insured disabled persons receive an additional benefit of 25 hours of PAS a month. The legislators made clear, however, that these services are limited to basic personal and domestic needs. Only severely disabled persons are eligible for these services[230] and the upper ceiling for monthly services is 25 hours at the maximum cost of 750 DM.[231]

For parents of disabled children (as well as non-disabled children under 8 years of age) there are additional in home health services within the system of health insurance. In case of hospitalization of one parent, they are eligible for household maintenance services if no other family member can take care of these tasks.[232]

c. Accident Insurance

Accident Insurance provides pensions, health care, rehabilitation and related benefits for persons who have been injured through work-related activities.[233] Besides medical and dental treatment, health care benefits include (nonmedical) personal assistance services.[234]

Eligibility criteria for personal assistance services is a certain degree of "helplessness". A person is eligible for PAS if she/he is so helpless that he/she cannot exist without PAS. If the person is less helpless, it is up to the insurance agency's discretion if PAS is provided.[235] However, the fact that a family member performs part or all of the PAS does not determine the injured person's degree of "helplessness".[236]

PAS can be provided for in cash or in kind. The latter implies that a nurse or another "suitable person" (home aid) is sent to the injured person's home by the insurance agency.[237]

It is worth mentioning that the law vests the insurance agency with authority to decide whether PAS benefits will be furnished in kind (at home or at institutions) or in cash.

Personal assistance allowances ranged from DM 384 to DM 1531 in 1983 and since then have been indexed annually.[238] The insurance agency determines the allowance amount in each case, according to regulations issued by the umbrella organization of Accident Insurance.[239] It is also up to each insurance agency's discretion to supplement the allowance if the costs of necessary PAS exceed the upper ceiling.[240]

It is worth mentioning that the law vests the insurance agency with authority to decide whether PAS benefits will be furnished in kind (at home or at institutions) or in cash. A requirement for institutionalization, however, is that the disabled person does not reject this form of benefit.[241] A survey conducted by the insurance' umbrella organization[242] shows that commonly benefits are granted in cash. Accordingly in 1977/78 144 persons received home-based or institutionalized PAS under Accidence Insurance, whereas 4,349 persons received PA allowances.[243]

2. Social Maintenance

Similar to Accident Insurance, the Social Maintenance system is designed to support injured persons who because of their injuries are disabled and/or economically disadvantaged.[244] Unlike Accidence Insurance, Social Maintenance covers a variety of non-work related injuries. The major ones are: Injuries incurred during military service in the former German Wehrmacht (the army of the Nazi-Regime) regulated by the Bundesversorgungsgesetz BVG (Federal Maintenance Act); injuries incurred during military service of the West German army, regulated by the Soldatenversorgungsgesetz (SVG Soldier's Maintenance Act); injuries incurred during social service[245] which is regulated by the Zivildienstgesetz (ZDG Social Service Act); injuries resulting from crime[246]; or caused by an epidemic[247].

The Federal Maintenance Act is the guide which all other laws of the social maintenance system use as a basic framework, and the benefits awarded by all the laws which apply to these instances are standardized.

Eligibility for PA allowance is linked to various levels of "helplessness". There are six levels of need for PA ranging from a daily regular need for PA (level I) with an allowance amount of DM 370 to more extensive PA needs with a ceiling amount of DM 1.835. disability matches which level of PA need. In any case, the recipient has to be quite "helpless" in order to be eligible for these benefits.

Besides various pensions[248] and benefits for dependent spouses, children or survivors, the Federal Maintenance Act provides for personal assistance in form of allowances.[249] Eligibility for PA allowance is linked to various levels of "helplessness". There are six levels of need for PA ranging from a daily regular need for PA (level I) with an allowance amount of DM 370 to more extensive PA needs with a ceiling amount of DM 1.835.[250] disability matches which level of PA need.[251] In any case, the recipient has to be quite "helpless" in order to be eligible for these benefits.

As under Accidence Insurance law, maintenance agencies (Versorgungsämter) have discretion to supplement these allowance benefits if the amount granted does not cover the actual costs of PAS.[252]

In case of illness the maintenance law also provides for home health services. Those services, however, are designed to prevent hospitalization, thus only medical tasks and basic personal care needs are encompassed. Furthermore, the law requires that they be prescribed by a physician and that no family member is able to perform these services.[253]

3. Social Assistance

Social Assistance is a means tested program which provides cash and in kind benefits for the poor. The Federal Social Assistance Act (Bundessozialhilfegesetz BSHG) applies only if no other benefits are available or self-help cannot be reasonably required.[254]

Nevertheless, the bulk of public expenditure on PAS is financed by Social Assistance. The rising caseload of PAS beneficiaries under Social Assistance[255] has been a problem for German welfare policy since at least the late 1970's.[256]

The Federal Social Assistance Act contains in kind and cash benefits for personal assistance services for disabled persons with various degrees of disability and different income levels. In any case, the person must be so helpless that he/she cannot exist without PA (first of four degrees of PA need).[257] Disabled persons with more extensive need for PA (second to fourth degree) are additionally eligible for a PA allowance which ranged from DM 299 to DM 812 in 1988.[258] The income ceiling varies accordingly from DM 810 plus rent costs and family subsidy (in case of marriage and children) for the first degree of PA need to DM 2.429 plus rent costs and family subsidy for the fourth degree.[259]

It is up to the social welfare agency to decide on PA needs in a given case. For some disabilities, however, PA need and severity of disability is assumed. An administrative regulation gives a list of disabilities that match the fourth degree of PA need.[260] In these cases the highest PA allowance has to be granted.

The PA allowance does not have to be spent on "professional" PAS. The legislators' intent was to vest these disabled persons with some financial resources in order to maintain the willingness of friends or family members to "help out".[261]

The allowance is an additional benefit to in kind PA, which has to be provided by the social welfare agency.[262] It is up to the beneficiary whether to apply for both benefits. However, if an individual receives both, the allowance amount might be curtailed down to 50%.[263]

In addition to in kind benefit and PA allowance, the Federal Assistance Act provides for a third benefit related to personal assistance services fur-

nished by family or household members of the disabled person or by "professional" assistants. For these attendants the Federal Social Assistance Act provides for benefits in the form of old age insurance contributions. With regard to family members, however, this is a discretionary benefit.[264]

In reality only very few family members or "professional" attendants take advantage of this benefit because commonly they are insured at the lowest level of old age insurance. The Supreme Administrative Court held that any old age insurance program which meets the General Assistance benefit amount is sufficient.[265] Such an old age insurance is not very attractive, because the pension amount equals the lowest social welfare benefit in West Germany.

By law, West German disabled children have to enroll in special schools for disabled children. In these settings they receive the assistance they need as related educational services. While sometimes exceptions are made, disabled children do not have a substantial right to integrated education.

If the disabled person is the head of a household in which nobody else is able to perform household maintenance tasks, he/she is eligible for a homeworker[266] so that other household members can be taken care of. However, this benefit is designed as a support for the beneficiary's dependents—on a short-term basis only.

C. Personal Assistance Programs With Respect to Education and Employment

1. Education

By law, West German disabled children have to enroll in special schools for disabled children. In these settings they receive the assistance they need as related educational services.

While sometimes exceptions are made, disabled children do not have a substantial right to integrated education.

In larger towns, like Hamburg, Berlin or Frankfurt several pilot projects in the area of integrated education have been implemented, modelled after existing programs in Sweden and Denmark.

Since no school or university is obliged to accommodate disabled students' needs, there is no public personal assistance service program for students. Demonstration projects have maintained an exceptional character.[267]

West German law requires those who employ more than 15 persons to hire a quota of six percent disabled persons.

Some post secondary-students, however, have found innovative ways to finance PA needs. The Federal Social Assistance Act contains a rather abstract benefit called integration assistance.[268] Under this provision, several services or allowances for poor disabled persons -such as car subsidies- may be granted. In a number of these cases social welfare agencies granted PAS for educational purposes.[269]

2. Employment

West German law requires those who employ more than 15 persons to hire a quota of six percent disabled persons.[270]

In order to enable disabled persons to work the employer has to adapt job premises, and the job itself, as long as the accommodation costs are "reasonable".[271] Accommodations include technical aids as well as access to the work premises. Employers do not have to provide for personal assistance, though. Personal assistance services may be provided by the labor agency through contracts with service agencies.[272]

However, few disabled individuals can apply for these benefits since most employers do not fulfill their employment obligations. Every third employer in West Germany does not employ even one disabled worker. Three out of four employers don't fulfill the six percent quota.[273] Although the state gives generous subsidies for employers who hire disabled workers, the majority prefers to pay the rather small compensation fee of DM 150 for each unfilled job of the six percent quota.[274] For this reason, significant PA programs for disabled employees have never been developed in West Germany.

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D. Personal Assistance Programs: Administration and Structure

As the description of the social security and welfare system shows, there are different ways in which a disabled person can receive personal assistance services. Provided with a PA allowance he/she will have to find an assistant on his/her own. Depending on the extent of need, as well as the benefit amount, he/she will employ an assistant, or give donations to family members or friends in order to maintain their "willingness to help out". A third way is to utilize an organization that furnishes personal assistance services and pay on a fee for service basis.

If in kind benefits for PA are granted, it is the administrative agency's (insurance agency, social welfare agency, etc.) responsibility to deliver these services. A few counties have employed home aids, but more commonly the agency will contract with a private PA organization for service delivery. In this case, payments are made directly to the organization on a fee for service basis.[275]

Except for health insurance law, the laws do not define the scope of PA tasks which are covered by PA benefits. Often this is a matter of bargaining with the administrative agency. In general, however, PA benefits are not confined to basic physical care services.[276]

Most of the six nongovernmental welfare organizations in West Germany offer such services. With increasing demand for PAS they have become more and more important to the Länder.

Another possibility is that a family member performs the necessary PA tasks and is reimbursed by the administrative agency.

During the last decade some efforts have been undertaken to analyze the situation of persons in need for PAS as well as the existing net of such services. The federal government has issued some surveys and pilot projects.

1. Dissemination and Financial Situation

At the end of the 70's a survey, conducted by a social science institute (SOCIALDATA) found that there were 2,530,000 West German persons (who were older than seven years old) in need of PAS.[277] This number represented 4.7% of the overall (German) population in West Germany at that time.[278] An additional 260,000 persons are institutionalized.[279] The same survey reported that only a small number of those in need of PAS receive those services from outside their family. While 63% received PA from family members and 31% were provided with help from relatives with whom they did not live[280] only 12% of the people were provided with PA by PA programs (on a fee for service basis).[281]

Although the survey dates back to 1980 and many service centers have been established in the late seventies[282] the situation has not changed markedly.

According to another survey, conducted in 1984/1985, there are 3889 centers or agencies that provide some sort of attendant services.[283] So far the increase of PAS centers has not decreased the PA work done by family members significantly. The report concludes that still over 50% of all consumers of PA receive these services from relatives exclusively. Ironically, this is especially true for the more severely disabled persons.[284]

At the end of the 70's a survey, conducted by a social science institute (SOCIALDATA) found that there were 2,530,000 West German persons (who were older than seven years old) in need of PAS. This number represented 4.7% of the overall (German) population in West Germany at that time. An additional 260,000 persons are institutionalized.

Most PAS centers are subsidized by the Länder governments. Meanwhile each Land has funding regulations that require a minimum standard of services provided (mostly health care, and domestic services), but these regulations differ from Land to Land.[285] However, this funding covers only the basic costs. Additionally the centers are reimbursed on a fee for service basis by the social agencies, mostly health insurance agencies, and local social welfare agencies. The actual reimbursement rate results from individual agreements between social (administrative) agencies and PAS centers. Currently PAS fees differ from center to center ranging from DM 3 to DM 25.[286]

According to a 1984 publication on PAS published by the umbrella organization of the six West German non-governmental welfare organizations, the issue of reimbursement rate has been a problem for a long time. Social agencies (insurance agencies, local welfare agency) try to keep the reimbursement rates low which in turn forces the PA centers to confine their services to "cheap" and "quick" tasks.[287]

As mentioned earlier, the bulk of PAS costs has to be carried by the local welfare agencies who are responsible for benefits according to the Federal Social Assistance Act. The funds have to be carried by the local governments or counties. In some counties

PAS expenditures amount to a third or half of the social budget.[288]

PAS benefits provided under the Federal Social Assistance Act are means-tested. Thus they are available only to disabled persons with low income (and assets) and who additionally meet the "helplessness" level required by the act. Therefore, although the Federal Social Assistance Act is currently the main funding source for PAS it does not mean that every PAS consumer receives financial assistance. According to the survey of 1980 more than 40% of all PA users do not receive any financial assistance at all.[289] These persons have to pay for PAS out of their own pockets or have to rely on their family's or friends' "willingness to help out" without any donations.

In 75% of the cases female family members or female friends take over these tasks.[290] Often these women receive no money at all for their PA work. Since only 12% of all persons in need of PA are employed, the majority will be unable to pay for PAS.

In 75% of the cases female family members or female friends take over these tasks.[290] Often these women receive no money at all for their PA work. Since only 12% of all persons in need of PA are employed, the majority will be unable to pay for PAS.

2. Goals, Administration, and Structure

Today most of the PA centers are organized by one of the six welfare organizations[291]. Only some counties employ nurses or home aids (called Familienpflegerinnen or Altenpflegerinnen).[292]

The scope of services provided differ from center to center. In general, however, major services are health care (furnished by nurses) and attendant services to the elderly. According to the report of the Deutscher Verein[293], 89% of the centers provide home-health care by certified nurses, and 75% furnish attendant services to the elderly, but only 49% offer domestic services and attendant services to younger persons.[294]

Thus, two thirds of all attendants who are employed by PA centers are medical personnel.[295]

Other employees are social workers, attendants with no professional background (former homemakers, students, unemployed, etc.) and volunteers and conscientious objectors who have to complete social services.[296]

The majority of PAS is furnished by what is called "Sozialstationen"[297]. Their services relate to the medical model of attendant services and do not allow much consumer involvement. Commonly, the disabled consumer has no choice on who is going to be his/her attendant and at what time.

From the beginning these services were not designed to cover long-term PA needs, but rather to provide for minimum medical care and home aid in order to shorten or prevent hospital treatment. This is why the typical Sozialstation employs six nurses and a smaller number of home aids and old person's attendants.[298] The typical client is an elderly person who needs medical care.

Only a few hours of services are furnished to a client of Sozialstation. For instance, the survey undertaken by Deutscher Verein shows that in the Länder Hamburg, Bremen, Niedersachsen and Hessen that a client received 3 to 13 hours of medical home services and 8 to 31 hours of PAS per month in 1984.[299]

Unlike Sozialstationen, AHDs—those PAS organized by members of the disability movement—were based on the intention to meet long-term (non-medical) PA needs from the very beginning. Accordingly, these centers employ few medical personnel and a large number of attendants who most often do not have a professional education with respect to attendant services.

Actually a vast number of these attendants are conscientious objectors. According to a survey including 11 AHDs they represent more than 60% of AHD employees.[300] The main reason for this high percentage of conscientious objectors among AHD attendants is AHD's and consumers' interest to keep the fee rates low. By law these attendants receive only a small wage during social service. By employing them as attendants, AHDs are able to offer comprehensive PAS at very low rates. In 1985 PAS fees in those 11 centers ranged from DM 2 to DM 25.[301]

In contrast to Sozialstationen the scope of services rendered by these centers to one consumer per month ranged from 8 hours to 313 hours of PA in 1984.[302] In addition many of these centers offer atten-

AHD's concept of comprehensive PAS is not only manifested by the service time rendered to one consumer but can be seen by the scope of tasks that are included in PAS. Encompassed are such various tasks as child care for disabled children, personal assistance to adults, domestic services, school and work assistants, sign language interpreters and readers.

dant referral services. The PA furnished by these attendants who are not AHD employees were not included in this survey.

AHD's concept of comprehensive PAS is not only manifested by the service time rendered to one consumer but can be seen by the scope of tasks that are included in PAS. Encompassed are such various tasks as child care for disabled children, personal assistance to adults, domestic services, school and work assistants, sign language interpreters and readers.

According to their philosophy AHDs try to allow as much consumer involvement as possible. While Sozialstationen commonly are directly reimbursed by the insurance agency or local welfare agency for services rendered to a consumer who qualifies for PA benefits, AHDs support a different method of reimbursement.

Eligibility requirements for PA benefits are vaguely defined by social welfare legislation, while administrative agencies have vast discretion when deciding on the actual benefit amount.

Benefits are paid directly to eligible consumers who then pay for the PAS they receive from AHD attendants or for attendant referral services. Consumer involvement is also supported by AHDs with respect to attendant training and choice of attendants. The latter, however, is often difficult to realize when the costs of PAS are covered by social benefits. Insurance agencies and welfare agencies have the authority to decide how much PA is necessary and up to which level the costs of PAS are reasonable. Often they reject grant benefits that cover the actual PAS costs if less expensive services are available. This administrative discretion may drastically restrict the consumer's choice. For example, a severely disabled female consumer of the AHD in Marburg (a town near Frankfurt), preferred to have only female attendants but needed 105 hours of PA per week. While the costs for PA performed by conscientious objectors in her case were DM 2.300, the same PA performed by female attendants would cost DM 6.800. The social welfare agency rejected grant benefits that would cover the costs for female attendants arguing that the same work done by male attendants (conscientious objectors) cost less than a third as much. Her interests in protecting her intimacy were considered to be outweighed by the public interest in saving social budget money.[303] Similar decisions were made when the costs for home-based PAS exceeded the costs for institutional care.

Thus the concept of consumer involvement is often difficult to realize for disabled consumers who have to rely on social benefits in order to cover their PA needs. Eligibility requirements for PA benefits are vaguely defined by social welfare legislation, while administrative agencies have vast discretion when deciding on the actual benefit amount.

In general insurance and welfare agencies have agreements with PA centers as to what is considered a "reasonable" PA fee, but agencies have the final decision in each case.

E. Evaluation of the West German System of Personal Assistance

West German Social Welfare Legislation provides for PA needs only at a minimum level. Old Age Insurance does not grant any PA benefits and the health insurance scheme covers only those PAS that are closely related to medical treatment.

Accident insurance and social maintenance have more comprehensive PAS provisions but only a few disabled persons qualify for these benefits. More frequently disability is caused by other reasons than by the particular accidents covered by these schemes. The majority of disabled people who need PAS are old people and another large group consists of people who have been disabled since birth or became disabled at an early age.

Thus, 90% of disabled persons who need PAS have to rely on welfare law.[304] The Social Assistance Act is designed to give a basic level of security only to poor people, i.e., those who are not covered (sufficiently) by any of the other social net systems.

Accident insurance and social maintenance have more comprehensive PAS provisions but only a few disabled persons qualify for these benefits.

But the need for PAS is not created by poverty. It is rather because most disabled persons who need these services have to spend most of their income and assets on PAS before they qualify for PAS benefits (under Federal Social Assistance Act), that they become a member of the poor population.

In a country in which more than 40% of the disabled population needing PAS does not receive any public assistance, one can hardly say that this population group is covered by the social net. But even those 60% of disabled people who do receive PA benefits are not covered sufficiently. Courts and statutory law require a very high level of "helplessness" before granting eligibility to any PA benefit.

The result is that disabled persons with less frequent need for PA are excluded from these benefits. Respectively, it is interesting to note that, as the surveys showed, actually a very small number of the more severely disabled receive PAS from outside their families.

At (regular) school or at work there are hardly any possibilities to receive PAS. There are only a few pilot projects rendering those services. The lack of PAS in these areas is due to several reasons.

For one, PAS are still considered home services by most politicians and administrative officials. Secondly, education law gives no substantial right to integration to disabled students. By law they have to enroll into the special school which matches their disability.[306] Only a very few disabled children escape segregated education in West Germany. Those parents who get their children admitted to regular school because of the teachers' and administration's "good will" hardly dare to request PAS.

The network of PAS centers is growing but still far from being comprehensive. The 1980 survey found that only 12% of the disabled population in need were reached by these centers.

Thirdly, although the legal situation is different with respect to employment because employers by law are obliged to hire disabled persons, the reality is very similar to education. The unemployment rate among the disabled population is high and few disabled people enter the mainstream of the labor force. Government officials undertake hardly any meaningful efforts to enforce the law which cannot be enforced by aggrieved disabled persons through lawsuits.

The network of PAS centers is growing but still far from being comprehensive. The 1980 survey found that only 12% of the disabled population in need were reached by these centers. By today the percentage may be higher but the majority of disabled persons will have to rely on family members and friends in order to cover their PA needs.

A common problem among all PAS centers is a bad financial situation. Unlike institution and nursery homes they receive reimbursement only for their actual PA services. Social welfare agencies and insurance agencies are generally unwilling to pay for administrative costs and the like. The funds from the Länder governments, which are designed to support these centers are insufficient. They are useful as a starting fund but they do not cover regular organizational costs.

Financial insecurity is one reason why most PAS centers provide services only to disabled persons with little PA need. Those customers can be furnished with cheap and quick services while persons with more extensive needs are more costly to serve.

Unlike Sozialstationen, the AHD's started out to meet the needs of those disabled persons. Based on the philosophy of independent living they wanted to offer an alternative to help from family members, rather than confining their work to support these families. In reality this was difficult to realize, though many of these centers now serve a significant number of persons with extensive PA needs.

Without using conscientious objectors as attendants those kind of services wouldn't be possible[306]. The present PAS policy in West Germany does not allow the employment of attendants who are paid adequate wages.

PAS performed by conscientious objectors have some disadvantages, however. One is that these persons are forced into this work because they have to do social service as a compensation for mandatory military service. It is their choice to be an attendant or do any other social work. But it is a choice between unwanted alternatives. Thus, they are often not particularly motivated to perform PA tasks which in turn affects the quality of PAS rendered to the consumer. Another problem is that these are all male attendants and many disabled women feel uncomfortable being assisted by men, especially if they need help with hygiene care and the like.

The labor status of attendants is a common problem. Low wages, rarely combined with social security or other benefits reveal that PA work is not highly recognized. Under those circumstances the concept of Independent Living is difficult to realize.

The AHD model allows more consumer control than the Sozialstation model, but both models have to be organized under the same economical and legal conditions. Administrative officials have the final decision on how many hours of PAS can be provided to a consumer. And reimbursement will be provided only for those services that have been granted by them. These are severe restrictions for the PAS centers as well as for the consumers.

In order to escape these restrictions some centers, founded more recently by disability activists, now favor a different concept. In reference to the CIL movement in the United States, they are called Centers for Independent Living. Among a variety of services they offer attendant referral services to disabled persons but they do not employ any attendants in order to provide PAS.[307]

VII. Conclusions

On April 12-14th 1989 approximately 100 disabled people from 14 countries (including Sweden, United States and West Germany) met at the European Parliament in Strasbourg for the first "European Conference on Personal Assistance Services for Disabled People".

The participants passed a resolution which involved the following principles on PAS:

"1. Personal assistance services are a human and civil right which must be provided at no cost to the user. These services shall serve people with all types of disabilities, of all ages, on the basis of functional need, irrespective of personal wealth, income, marital and family status.

2. Personal assistance users shall be able to choose from a variety of personal assistance models which together offer the choice of various degrees of user control. User control, in our view, can be exercised by all persons, regardless of their ability to give 'legally informed consent'.

3. Services shall enable the user to participate in every aspect of life, such as home, work, school, leisure, travel and political life etc. These services shall enable disabled people, if they so choose, to build up a personal and family life and fulfill all their responsibilities connected with this.

4. These services must be available long-term for anything up to 24 hours a day, seven days a week, and similarly on a short-term or emergency basis. These services shall include assistance with personal bodily functions, communicative, household, mobility, work and other related needs. In the assessment of need the consumer's view must be paramount.

5. The funding authority shall ensure that sufficient funds are available to the user for adequate support, counselling, training of the user and the assistant, if deemed necessary by the user.

6. Funding must include assistant's competitive wages and employment benefits, all legal and union-required benefits, plus the administrative costs.

7. Funding shall be a legislative right and payment must be guaranteed regardless of funding source or local government arrangements. Funding shall not be treated as disposable/taxable income and shall not make the user ineligible for other statutory benefits or services.

8. The user should be free to appoint as personal assistant whoever s/he chose, including family members.

9. No individual shall be placed in an institutional setting because of lack of resources, high costs, sub-standard or non-existent services.

10. There shall be a uniform judicial appeal procedure which is independent of funds, providers and assessors; is effected within a reasonable amount of time and enables the claimant to receive legal aid at the expense of the statutory authority.

11. In furtherance of all the above, disabled people and organizations controlled by them must be decisively involved at all levels of policy making including planning, implementation and development."

An advantage of the Swedish system is that eligibility to PAS and benefits is not linked to the person's income. Unlike the systems of the United States and West Germany, Sweden's social welfare legislation recognizes that PA needs are not caused by poverty and that disabled persons of all income groups may need those services in order to have equal opportunities in society.

The PAS systems in Sweden, the United States and West Germany are far from fulfilling these principles. However, each system seems to have its good and bad points.

Various Advantages

An advantage of the Swedish system is that eligibility to PAS and benefits is not linked to the person's income. Unlike the systems of the United States and West Germany, Sweden's social welfare legislation recognizes that PA needs are not caused by poverty and that disabled persons of all income groups may need those services in order to have equal opportunities in society. Otherwise, disabled persons would have to earn a higher income than the average citizen to be able to cover such disability-related costs. Sweden is also exemplary with respect to reimbursement policy towards relatives of disabled persons who provide PA. To pay these family members for their labor is a necessary response to those social and demographic changes of society, that were mentioned earlier.

An advantage of the American system is the diversity among the programs. Because state and federal government did not dictate one uniform PAS model for each program, innovative forms of PAS with significant consumer involvement could be developed.

An advantage of the American system is the diversity among the programs. Because state and federal government did not dictate one uniform PAS model for each program, innovative forms of PAS with significant consumer involvement could be developed. It seems though, that now the time has come to set the path for a more uniform national system in order to overcome the shortcomings that grew out of piecemeal attempts to address isolated problems of PAS.[308]

An advantage of West German's personal assistance law may be that it clearly distinguishes between health care and personal assistance, which helps—at least to a certain extent—to avoid the medical model of PAS that requires a doctoral treatment plan and health professionals to perform the services.

An advantage of West German's personal assistance law may be that it clearly distinguishes between health care and personal assistance, which helps—at least to a certain extent—to avoid the medical model of PAS that requires a doctoral treatment plan and health professionals to perform the services.

A commendable West German benefit is the special benefit of PAS allowance provided for under the Federal Social Assistance Act in addition to PAS benefits. Except for the eligibility criteria of low income and high degree of "helplessness", this benefit is an important tool for independent living. It is granted at a certain degree of disability no matter whether the money will actually be spent on PAS. Most disabled people use this money, according to the legislators' intent, for motivating their friends' and relatives' willingness to "help out" on a "voluntary" basis. This might be important in emergency situations, when the assistant suddenly becomes ill and no other assistant is available. Also, there are situations when the assistant is not on duty but a few PA tasks are needed. Or a disabled person might need only a little PA every day and friends are willing to do these tasks but do not want to have a financial relationship with the disabled friend. In these cases it is important that the disabled person is able to give little gifts or invite these friends to dinner or movie. This helps to keep the friendship on equal grounds. Since the welfare agency has no authority to check on how the money is spent, the disabled person is free to use this money for whatever s/he deems reasonable.

In my view the disability allowance is also an incentive to avoid extensive use of public PAS because it allows an individual to choose a middle road between labor relationship and altruism.

Disadvantages

The disadvantages of each country's system have been mentioned in each chapter. Therefore only a few should be named here. Common to all systems is that

The question of costs is certainly an important factor in social policy but it should not be the only one.

severely disabled people are more or less excluded from public PAS. One explanation may be that community-based PAS are a relatively new form of social services and more experience is necessary to overcome the general assumption that institutional care is the best alternative for these people. However, at least Sweden has had a long tradition of PAS for disabled people. And meanwhile each country has some sort of pilot project which proved that independent living is possible for severely disabled individuals. Rather, it seems to be a matter of costs, e.g. the fact that furnishing PAS to some disabled people might be more expensive than institutional care. The question of costs is certainly an important factor in social policy but it should not be the only one.

The independent living movements grew out of disabled peoples' struggle against disability-based discrimination which has different forms. One is the attitude of patronizing and pity and another is segregation and institutionalization. The independent living model of PAS was developed by disabled individuals who were experts with respect to these kinds of discrimination. They understood that a shift of paradigm in disability policy was necessary. The independent living concept provides this new paradigm, one in which disabled people have a voice in their own future. It fosters a new sense of dignity and respect which frequently has been denied to disabled people. Viewed from this perspective, social policy with respect to PAS for disabled people cannot be determined by the matter of costs only, but rather by the goal to undo past discrimination.

In all three countries the systems of PAS are more commonly organized according to the medical model which assigns the helpless and passive role to disabled people, rather than supporting the principle of consumer control. However, the point could be made, that the same is true for some services that are rendered to non-disabled (as well as disabled) persons.

In all three countries the systems of PAS are more commonly organized according to the medical model which assigns the helpless and passive role to disabled people, rather than supporting the principle of consumer control. However, the point could be made, that the same is true for some services that are rendered to non-disabled (as well as disabled) persons. For example teachers in schools are assigned to children, rather than being chosen by their parents. There are similar situations with respect to medical services. Sometimes a patient has no influence on who is going to be his/her doctor for visit or surgery because again, it is a matter of assignment. Do the disability movements, then demand more choices and control for disabled people than their non-disabled peers have?

Again one has to take the antidiscrimination component into account in order to answer this question. There is a profound difference between the choice and control over who is going to teach my child and the choice and control over and who is going to put me at what time to bed. It is not only that the assistance disabled people need often is more intimate, although this is a critical factor. To have choice and control with respect to PAS simply means to decide on the most basic things in daily life. And while, of course, free choice with respect to medical services is an important right as well, demanding control and choice with respect to PAS, does not mean to ask for extraordinary privileges for disabled individuals not available to other citizens. Rather, it means to demand equal opportunities with respect to those decisions a disabled person takes for granted.

The independent living model does not prescribe a narrow form of PAS for every non-disabled consumer. Disabled people as well as non-disabled vary in their desire or ability to be self-reliant. While there are persons who want to hire, fire and train their own assistants, there are others who want to delegate attendant management and training to a service agency.

The independent living model does not prescribe a narrow form of PAS for every non-disabled consumer. Disabled people as well as non-disabled vary in their desire or ability to be self-reliant. While their are persons who want to hire, fire and train their own assistants, there are others who want to delegate attendant management and training to a service agency. And there are those, who because of their disability, are unable to totally manage their own assistants but desire some other level of control.

Therefore, a full range of options should be available.

Another issue, that is raised by the principle of consumer control is the question of needs assessment. Activists of the independent living movement say that (often) the disabled individual is the best expert on his/her disability. Nevertheless, any public PAS system must have some needs assessment procedure according to which an individual case will be decided. There has to be a standard revealing who is eligible for PAS and for how much. It is unrealistic to assume that this decision could be left with the disabled consumer without having the problem of misuse of social benefits. Disabled persons are not superior to other human beings receiving social welfare or social security benefits. On the other hand, the analysis of the PAS systems in Sweden, West Germany and the United States, shows, that a great number of disabled persons do not receive the assistance they need because of legal or administrative restrictions.

In West Germany many disabled people are excluded from public PAS because eligibility is linked to a high degree of functional limitations. Generally, the laws require that the recipient be unable to survive without PAS.

In West Germany many disabled people are excluded from public PAS because eligibility is linked to a high degree of functional limitations. Generally, the laws require, that the recipient be unable to survive without PAS. However, PAS in the sense of independent living should not be confined to tasks of basic physical care such as bathing, feeding, dressing, etc. Rather PAS should enable the recipients to make a living in their communities. Therefore, eligibility should be linked to the time of PA in need—say one hour per week/ per month as a minimum—no matter what tasks are necessary.

An example of administrative restriction was given with the case of the German disabled woman to whom female attendants were denied because utilizing conscientious objectors was a cheaper option. Social welfare agencies often are more concerned with the balance of their social budget than with needs of the citizens they are supposed to serve. Legislators support this kind of administration when they pass laws involving programmatic commitments to PAS that are not followed by augmented social budgets.

A needs assessment procedure that supports the independent living concept has to take the consumer's interest as well as financial aspects into account. Furthermore, the right balance between too much paternalism and privacy invasion on the one hand and an abstract eligibility formula which is bound to lead to mistakes has to be found. For instance it would not be helpful to create a list of identified disabilities and allocate a certain amount of PA benefits to each type of disability. People with identical disabilities often differ greatly in their needs for assistance.[309]

In its draft bill on PAS, which is modelled on the American Education For All Handicapped Children Act[310], the World Institute on Disability proposes the following assessment process:

> *"Section 5 (a) NEEDS ASSESSMENT AND SERVICE PLANNING shall be the responsibility of a government or non-profit agency (which does not provide personal assistance services) designated in each locality by the state. This agency shall —*
>
> (1) perform assessments of prospective or current recipients in order to determine —
>
> (A) their eligibility for services;
>
> (B) the extent to which they are able to perform each activity of daily living;
>
> (C) the extent to which they will be capable of managing their own personal assistance service; and
>
> (D) if there are special circumstances which affect their need for personal assistance;
>
> (2) Use the information gathered during the assessment to prepare a written Individual Service Plan for each recipient. The Individual Service Plan shall specify—
>
> (A) the number of hours and types of services to be provided;
>
> (B) whether the services will be provided by individual providers or agency employees;
>
> (C) whether or not the recipient is capable and desirous of exercising total responsibility for managing her or his own personal assistance services, and if not, whether the recipient can acquire the necessary management skills through training pursuant to Section 5 (c)(2)(E) above;

or whether management assistance will be provided by an outside agency pursuant to Section 5(c) (1) above;

(3) Give full consideration(weight?) to the opinions and desires of the recipient or his or her representative during the assessment process and preparation of the Individual Service Plan."[311]

The independent living movements have achieved great success in a short period of time. They have taken a stand against disability-based discrimination. They have proved that disabled people need not live in institutions, or be educated in separated school settings or work in sheltered work shops if social and environmental changes are undertaken. The establishment of a PAS system, based on the independent living concept, is one of those necessary transformations.

WID's proposal is a highly individualized evaluation process. While it assures exact needs assessment and that services be provided in various forms, it might also be accompanied by some restrictions regarding the recipient's choice. For instance, s/he has to know from the beginning what PAS model fits her/his needs. Once the Individual Service Plan is set up, the consumer will be confined to the prescribed form of PAS.

How much weight is given to the recipient's voice within the needs assessment process thus seems to be essential. One safeguard would be a comprehensive appeals procedure which enables the recipient to enforce a substantial right to PAS.

The independent living movements have achieved great success in a short period of time. They have taken a stand against disability-based discrimination. They have proved that disabled people need not live in institutions, or be educated in separated school settings or work in sheltered work shops if social and environmental changes are undertaken. The establishment of a PAS system, based on the independent living concept, is one of those necessary transformations. A transformation which will probably be costly and require legal reforms.

At least for the United States and West Germany it looks like legal reforms with respect to PAS are predictable for the future because in both countries there are ongoing legal debates on this issue. The discussion on how to cope with the rising problem of long-term assistance need in the future is also taking place in groups beyond the disability movements. The latter have now the responsibilities to reach out and form coalitions with all those who have a stake in the outcome and invoke or influence the legislative debates.

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Footnotes

[1] U.S. Commission on Civil Rights. (1983) *Accommodating the Spectrum of Individual Abilities.* Clearinghouse Publication 81, (hereinafter cited as: U.S. Commission on Civil Rights. (1983) Accommodating); Litvak S. et al. (1987) *Attending to America: Personal Assistance for Independent Living,* World Institute on Disability, Berkeley CA

[2] One famous example of those attitudinal barriers in the labor force is the story about the automobile manufacturer in Detroit who required that workers with amputations wear artificial limbs. His motivation was not that those limbs would improve the disabled workers' merits but he was concerned "for the working morale of the men." The presence of a disabled person made people feel uncomfortable. That was in 1925 and the prevailing attitude at that time was to hide disability in order to accommodate for a nondisabled labor market.
Berkowitz, E.D. (1988) *Disabled Policy, America's Policy for the Handicapped,* Cambridge University Press, p. 184

[3] For the United States: Scotch R.K. (1984) *From Good Will to Civil Rights,* Temple University Press, Philadelphia

[4] Stoddard S. (1978) "Independent Living: Concept and Programs." *American Rehabilitation 3,* p. 2

[5] as well as professor and chair of the Department of Sociology, Brandeis University

[6] Litvak S., Zukas H., Heumann J. (1987) *Attending to America. Personal Assistance for Independent Living.* World Institute on Disability, Berkeley, CA, p. iv;

[7] Unlike old age, race and gender, disability resists precise definition and measurement. Determining disability involves social judgement as well as a combination of physical, economic, psychological and environmental conditions.
For a more detailed discussion: Berkowitz E.D. (1987), ibid., p. 3 et.seq, U.S. Commission on Civil Rights (1983) *Accommodating* ibid., pp.

[8] Litvak S. et al. (1987), ibid. p. 1;

[9] Apparently this definition does not solve the difficult problem of defining disability

[10] In Europe the first institutions for disabled persons were built in the end of the middle ages. In the United States institutional care for disabled persons emerged in the nineteenth century.
For Europe see: Perl O. *Krüppeltum und Gesellschaft im Wandel der Zeit.* Gotha 1926; Biesalski K. *Grundriss der Krüppelfürsorge.* 3. Aufl. Leipzig 1926;
For the development in the United States see: Varela R.A. "Changing Social Attitudes and Legislation Regarding Disability" in:Crew, N.M., Zola I.K., et al. (1983) ibid.;
Care outside institutions in form of homemaker-home health services was offered only by private charitable organizations in the beginning of the nineteenth century in Europe and twentieth century in the United States.
See: Laurie G. (1977) *Housing and Home Services for the Disabled.* Harper & Row, Inc., Maryland

[11] Scotch R.K. (1984), ibid.

[12] Scotch R.K. (1984), ibid., p. 13

[13] DeJong G. (1983) "Defining and Implementing the Independent Living Concept". in: Crewe N. and Zola I.K. (1983) ibid.

[14] see: DeJong G. (1978) *The Movement for Independent Living: Origins, Ideology, and Implications for Disability Research.* Medical Rehabilitation Institute. Tufts-New England. p. 20 et seq.

[15] DeJong G. (1983) ibid., p. 12

[16] DeJong G. (1983) ibid., pp. 20;
Wolfensberger W. (1973) *The Principle of Normalization in Human Services.* Downsview: National Institute on Mental Retardation;

[17] Dybwad once explained this principle this way: "...normal on our earth is trouble and trifle, trial and tribulation and the handicapped person has the right to be exposed to it."
Dybwad G. (1973) "Is Normalization a Feasible Principle of Rehabilitation?" in: *Models of Service for the Multihandicapped Adult,* United Cerebral Palsy of New York City, Inc., New York, p. 57

[18] Illich I. (1976) *Medical Nemesis: The Expropriation of Health.* Pantheon, New York;

[19] DeJong G. (1978), ibid., p. 22;

[20] Litvak S. et al. (1987) ibid., p. 10;

[21] DeJong G. (1983) "Attendant Care", in: Crewe, N. (1983) ibid., p. 157;
Frieden L. (1983) "Understanding Alternative Program Models", in: Crewe N., Zola I.K., (1983) ibid., p. 62-72;

[23] The founders of those Centers were not the first disabled persons in the United States, who started out to organize personal assistance services on their own. From the mid-50's a variety of projects such as apartment living arrangements, transitional projects and organized home services were initiated by individuals or groups on assistance users. Many of them have failed or faded away. See: Laurie G. (1977) ibid.;

[24] Department of Rehabilitation, (1982) *The California Independent Living Centers.* Sacramento, CA, p. 5; Laurie G. (1977) ibid., p. 129;

[25] DeJong G. (1979) ibid., p. 437; Cole J.A. (1979) "What's new about Independent Living?", *Archives of Physical Medicine and Rehabilitation No. 10.* p. 459

[26] Cole G.A. (1979) ibid., p. 459

[27] Frieden L. (1983) ibid., p. 62-72

[28] For example a survey on ten California CIL's reveals the following list of services: "Attendant referral, general advocacy, peer counselling, housing assistance, identification of accessible housing, benefits counselling, legal advocacy, personal advocacy, transportation, employment preparation, financial counselling, special services for the deaf, special services for the blind, vehicle access (repair modification), attendant training, substance abuse counselling"
see: Department of Rehabilitation (1982) ibid., p. 4

[29] The other four key IL services are: peer counselling, skills training, transportation and housing. See Crewe N., Zola I.K. (1983) IBID., P. 155

[30] Laurie G. (1982) "Independent Living" in: Vereinigung Integrationsförderung e.V. (VIF) München. (1982) *Behindernde Hilfe oder Selbstbestimmung der Behinderten?* München p. 129

[31] The "father" of the fokus model is Sven Olov Brattgard, today at University of Götebord, Department of Handicap Research, Sweden

[32] Brattgard S.O. (1982) "FOKUS—Brennpunkt der Integration Behinderter in Schweden" in: Vereinigung Integrationsförderung e.V. (VIF) München. ibid p. 45;
Ratzka A.D. (1986) *Independent Living and Attendant Care in Sweden: A Consumer Perspective.* World Rehabilitation Fund, Inc.: New York, NY, p. 32;

[33] Ratzka A.D. (1986) ibid., p. 32

[34] Ratzka A.D. (1986) ibid., p. 32

[35] With participants from the United States (Judith Heumann and Ed Roberts, World Institute on Disability, Berkeley, California) and from the United Kingdom (Ken Davis, Derbyshire Coalition of Disabled Citizens and Neill Slatter, Hampshire Independent Living Center); Ratzka A.D. (1986) ibid., p. pp n. 65

[36] Ratzka A.D. (1986) ibid., p. 33

[37] In some of the "boenderservice" complexes heavy conflicts between assistants and administration on the one side and tenants on the other were caused by documents that were prepared in order to rationalize the service. Some of the documents were produced secretly and besides needs assessment contained such information as tenants' characteristics and behavioral customs. See: Ratzka A.D. (1982) "Schweden—Wunderland der Integration?" in: Vereinigung Integrationsförderung (VIF) München, (1982) ibid., p. 63

[38] Ratzka A.D. (1986) ibid., p. 44

[39] Ratzka A.D. (1988) "Aufstand der Betreuten. STIL—Persönliche Assistenz und Independent Living" in: Mayer A., Rütter J. (ed.) *Abschied vom Heim. Erfahrungsberichte aus Ambulanten Diensten und Zentren für Selbstbestimmtes Leben.* München AG SPAK—Publikationen, pp. 183

[40] Those are:

(1) Caritas (Organization of the Catholic Church)

(2) Diakonisches Werk (Organization of the Protestant Church)

(3) Arbeiterwohlfahrt (Social Democrats oriented welfare organization)

(4) Deutsches Rotes Kreuz (German Red Cross)

(5) Zentralwohlfahrtsstelle der Juden in Deutschland (welfare organization of Jews in Germany)

(6) Paritätischer Wohlfahrtsverband (coalition of a wide range of different non-clerical "free" welfare organizations)

[41] Thalidomide was a drug against pregnancy nausea (and other indications) which caused fetal damages and resulted in the birth of disabled children without arms, legs or other organs. It was on the market between 1957 and 1961 in West Germany and seven other countries, but not in the United States.

[42] These institutional and home-based services complement the state's health and social services.

[43] for a general analysis see: Bauer R., Diessenbacher H. (ed.) *Organisierte Nächstenliebe.* Opladen. Westdeutscher Verlag. (1984);

[44] The mental disability organization "Lebenschilfe für Geistigbehinderte e.V." also owns sheltered workshops and homes for mentally disabled.

[45] Most of the new disability groups rejected the

celebrations of the year as an attempt to disguise the real deficiencies of disability policies. They organized in order to disturb these celebrations. Several activities such as a blockade on the national opening ceremony in January 1981 and the "crippel tribunal" concerned with human rights violations against disabled persons which took place in December 1981 achieved significant media attention. See: Mayer A. (1988) "Behinderteninitiativen in der Bundesrepublik" in: Steiner G. (ed.) (1988) *Hand—Fussbuch für Behinderte.* Fisher Taschenbuch Verlag GmbH, Frankfurt am Main. p. 165; Degener Th. (1982) "Das Krüppeltribunal 1981" in: Holtz K.L. (ed.) (1982) *War's das? Eine Bilanz zum Jahr der Behinderten.* Heidelberg—Schindele. p. 26

[46] So far no survey on the number and scope of services of those personal assistance centers has been conducted. From my experience as a legal counselor at one of the largest centers (feb e.V. Marburg), where we did a lot of national networking, I would estimate the number of these centers between 40 and 50.

[47] Rüggeberg A. (1982) "Vereinigung Integrations-Förderung e.V. -VIF" in Vereinigung Integrationsförderung (VIF) München (1982) ibid., p. 262;Rütter J. (1986) *Die Entstehung und Entwicklung Selbstorganisierter Ambulanter Hilfsdienste für Behinderte.* Materialmappe der AG SPAK (Arbeitsgemeinschaft Sozialpolitischer Arbeitskreis). München.

[48] For example IF is one of the few centers that provide reading services to blind persons on a regular basis.

[49] Military service of 16 months is mandatory for men in West Germany. Conscientious objectors have to serve in social service for 20 months at any non-profit organization whose services has been acknowledged as being for the benefit of the public. Thus they cannot be directly hired by a disabled person.

[50] Degener Th. (1985) "Ambulante Dienste ... nicht mehr in Heimen leben" in: Die Grünen. BAG Behindertenpolitik bei den Grünen. (1985) *1995—Ende der Pflegeheime.* Hamburg. p. 40

[51] Holgersson L., Lundström S. (1975) *The Evolution of Swedish Social Welfare.* The Swedish Institute. Sweden

[52] Though not explicitly mentioned, a right to welfare benefits that meet at least subsistence level is covered by a combination of constitutional provisions:
Grundgesetz [GG] art. 1 (1) (right to human dignity) and art. 2 (2) (right to live) (W. Germ)
See: Judgement of June 24, 1954, V. Bundesverwaltungsgericht, (W.Ger.), Bundesverwaltungsgericht Entscheidungssammlung [BVerwGE] 1, p. 159 (162); A right to welfare is expressively assured in the Federal Social Assistance Act of 1973 (BSHG) in section 4 (1). Social insurance rights, gained by contributions are considered quasi-property rights and are protected under the property clause in Art. 14 of the Constitution (Grundgesetz). See: BSGE 45, 251 (supreme social court); Dicke D. Rdnr. 20 zu Art. 14 in: von Münch, I. (1981) ibid.

[53] Bley H. (1982) *Sozialrecht,* 4. Aufl. Frankfurt am Main; Berkowitz M., Dean D. (1987) "Disability Systems: A Cross National Comparison" in Duncan B., Woods D. (1987) *Social Security Disability Programs: An International Perspective.* World Rehabilitation Fund, Inc. New York, N.Y. p. 13

[54] *Olmstead v. United States,* 277 U.S. 438, 478; 48 S.Ct. 564, 572 (1928) (Justice Brandeis dissenting); *Bowers v. Hardwick,* 106 S.Ct. 2841, 2848 (1986) (Justice Blackmun, dissenting)

[55] However, recent judicial changes in attitude towards welfare has granted some constitutional protection against arbitrary granting or denying of benefits by governments.
For constitutional protection against arbitrary denial or granting see: *Shapiro v. Thompson,* 394 U.S. 618 (1969) and *Goldberg v. Kelly, 397 U.S. 254 (1970). Both cases involved welfare benefits for families with dependent children (AFDC). While the Court recognized welfare interests as somehow constitutionally protected, it also clearly stated the limits. In Fleming v. Nestor,* 363 U.S. 603 (1960) and Richardson v. Belcher, 404 U.S. 78 (1971) the court stated that social insurance benefits, such as old age pension, though "earned" through contributions, are neither constitutionally protected property nor contractual rights. Again it was recognized that those benefits represent an interest which is protected by the Constitution. This distinction has been upheld in subsequent cases such as *Weinberger v. Wiesenfeld,* 420 U.S. 636 (1975) and *Califano v. Goldfarb,* 430 U.S. 199 (1977).

[56] Under this principle, the federal government offers grants-in-aids to state programs. While the administrative responsibility rests with the states, implying such tasks as fixing the benefit level as well as developing eligibility criteria, the federal program, standards which States have to comply with in their own state plans. But states are free to offer their own programs in addition to the federally funded program. Other federally funded programs are administered by federal agencies, each of which has is own regulations and procedures.
See: LaFrance A. (1978) *Welfare Law: STructure and Entitlement.* Netshell series. West Publishing Co., St. Paul, Minnesota, P. 63

[57] For a comparison of social welfare programs see: Leibfried S. (1979) "The United States and West

German Welfare Systems: A Comprehensive Analysis." 12 *Cornell International Law Journal* 174-198;
For a general description see: LaFrance A. (1978) Ibid., Chapter I;

[58] Compare: Mitchell P. (1987) "Definitions of Disability" in Duncan B., Woods D (1987) ibid., p. 13

[59] Such disabilities as: blindness, deafness, loss of limbs, mental disabilities, etc.

[60] For instance my case. I studied law at Frankfurt University (West Germany) and at UC Berkeley. I needed to employ two personal assistants in Frankfurt whereas in Berkeley, due to a computerized library system, a general copy service and a disability accommodation policy (in my case: stools were organized so that I could reach computers with my feet, rams and elevators allowed me to carry my books around on a skateboard), no special PAS was necessary.

[61] There is an ongoing discussion on whether or not progress in technology as well as other forms of assistance—by dogs or monkeys or robots—can and should obliterate PAS provided by human beings. See: Crewe N., Harkins A. (1983) "The Future of Independent Living" in Crewe N., Zola I.K. (1983) ibid., p. 327, and:
Foulds R., RESNA (ed.) (1986) *Interactive Robotic Aids. One Option for Independent Living.* World Rehabilitation Fund, New York, NY; I see these visions with some skepticism and strongly recommend to pursue the independent living principle of each disabled person's right to choose".

[62] In the United States the law requires public transportation to be accessible and relatively major efforts have been made to meet the needs of disabled commuters. This is not the case in Sweden and West Germany. In Sweden, however, municipalities by law have to provide paratransit service, which implies house to house travel service in special vans or taxis for disabled citizens. In West Germany some efforts have been made in this direction during the last decade, though the service is discretionary and in general persons are entitled to only a couple of rides (6-10) monthly. Disabled workers and sometimes students may be provided with car allowances covering the costs for adapting a personal car. These different transportation situations in each country have significant influence on whether or not independent living is possible for disabled citizens.

[63] As a measurement for the scope of PAS tasks, I refer to the definition developed by the World Institute on Disability cited above.

[64] Holgersson L., Lundström S. (1979) ibid., p. 12

[65] Carlsson B. and F. (1982) *Social Welfare and Handicap Policy in Sweden.* The Swedish Institute. Sweden. p. 15

[66] It is common to distinguish elderly persons from disabled people with regard to social welfare policy. As to the issue of PAS, the author of this thesis does not favor this distinction, since a person who needs personal assistance because of functional limitations due to old age is as disabled as a younger person with the same functional limitations caused by an accident. The term "disabled person" as used in this thesis includes persons of all ages. However, since many publications distinguish between the groups, the term "elderly persons" will be mentioned sometimes.

[67] The Swedish Institut. (1987) "Social Insurance in Sweden". *Fact Sheets on Sweden.* Sweden (FS 5 t Ok)

[68] The Swedish Institute (1987) "The Health CAre System in Sweden" MIFact Sheets on Sweden. (FS 76 o Vpb), Sweden ibid.

[69] forsberg M. (1984) *The Evolution of Social Welfare Policy in Sweden.* The Swedish Institute. Sweden, p. 46

[70] The Swedish Institute (1987) "Social Insurance in Sweden" ibid.

[71] Private health care exists on a limited scale. Within the inpatient sector there are some private nursing homes for long-term care. Physicians rarely work in private offices fulltime.

[72] The Swedish Institute. (1987) "The Health Care System in Sweden" ibid.

[73] Forsberg M. (1984) ibid., p. 60

[74] Parents (of whom one abstains from gainful employment in connection with childbirth) are entitled to nine months leave with compensation of 90% of their gross income during the first six months and a fixed amount (60 SEK per day) for the last three months.
See: The Swedish Institute. (1987) "Social Insurance in Sweden" ibid.
The publication cites an exchange rate of: "SEK 1 = $0.16"

[75] ibid.

[76] The base amount adheres to the general price level and is fixed annually. As of 1987 it was SEK 24.1000. See: The Swedish Institute (1987) "Social Insurance in Sweden" ibid.

[77] The Swedish Institute (1987) "Social Insurance in Sweden" ibid.
Although most pensioners in Sweden have lower average income than younger people, the number of pensioners living below the poverty level is said to be extremely low.

See: Sundström G. (1987) *Old Age Care in Sweden. Yesterday, today...tomorrow?* The Swedish Institute. Sweden. p. 20

[78] Carlsson B. and F. (1982) ibid., p. 43

[79] The Swedish Institute (1988) "Support for the Disabled in Sweden" *Fact Sheets on Sweden,* (FS 87 f Ohf)

[80] Some categories of disability, such as blindness and deafness are always considered to require PAS with the result that disability allowance is granted automatically.
See: The Swedish Institute. (1988) "Support for the Disabled in Sweden". ibid.

[81] Holgersson L., Lundström S. (1979) ibid., p. 18;

[82] The Swedish Institute. (1988) "Support for the Disabled in Sweden", ibid.

[83] depending on the need for assistance due to the disability.

[84] Forsberg M. (1984) ibid., p. 52

[85] cited after Forsberg M. (1984) ibid., p. 65

[86] Ratzka A.D. (1986) ibid., p. 17; The Swedish Institute. (1988) "Support for the Disabled in Sweden". ibid; Carlsson, B. and F. (1982) ibid., p. 40

[87] The Swedish Institute (1988) "Support for the Disabled in Sweden". ibid.

[88] supra p. 39;
The Swedish Institute (1988) "Support for the Disabled in Sweden". ibid

[89] Ratzka A.D. (1986) ibid., p. 17

[90] Forsberg M. (1984) ibid., p. 41

[91] Carlsson B. and F. (1982) ibid. p. 41

[92] Up to 25% of a secretary's average full-time salary. See: Ratzka A.D. (1986) ibid. p. 19

[93] Sundström G. (1987) ibid., p. 30; Ratzka A.D. (1986) ibid., p. 38

[94] The municipal governments recover about 7% of the program's costs in this way.
See: Sundström G. (1984) ibid. p. 30

[95] A statistical report of 1982 provided by the National Central Bureau of Statistics reveals, that more than two thirds of all customers are senior citizens. 20% of all persons of 65 years and older and 43% of all swedes above 79 utilize the service. cited after: Ratzka A.D. (1986) ibid., p. 26

[96] Ratzka A.D. (1986) ibid., p. 27

[97] Ratzka A.D. (1986) ibid., p. 26

[98] Recently some efforts have been undertaken to try out new experiments of cooperation between municipal home helper service and county medical care system. One of these experiments consists of night and weekend patrol groups of a home helper and a nurse. Part of their night schedule is booked for regular assignments; the rest is reserved for emergency visits in response to alarm.
See: Sundström G. (1987) ibid., p. 39

[99] supra p. 19

[100] Ratzka A.D. (1986) ibid., p. 27; Sundström G. (1987) ibid., p. 30

[101] In Stockholm, for example, a disabled person is entitled to a maximum of 15 hours a month for a maximum of three outside activities at five hours each.
See: Ratzka A.D. (1986) ibid., p. 30

[102] Sundström G. (1987) ibid., p. 32

[103] Ratzka A.D. (1986) ibid., p. 28.

[104] Generally a two-week course of training is given as a preparation for work to an assistant. For reasons of work environment, assistants are not allowed to do certain heavy physical tasks.
See: Sundström G. (1987) ibid. p. 30

[105] Ratzka A.D. (1986) ibid., p. 28

[106] Ratzka A.D. (1986) ibid., p. 37

[107] Some criticism has been raised however, with regard to the consequences of compartmentalization between home helper service and inhome medical service. For the disabled person this means to deal with two different administrations (county council and municipal social welfare office) if their disability implies chronic medical needs.
See: Ratzka A.D. (1986) ibid., p. 29

[108] Sundström G. (1987) ibid., p. 35

[109] Ratzka A.D. (1986) ibid., p. 37

[110] See: Ratzka A.D. (1986) ibid., p. 36

[111] Ratzka A.D. (1986) ibid., p. 39

[112] Reported as an example which happened in Stockholm by Ratzka, A.D. (1986) ibid., p. 40

[113] Ratzka A.D. (1986) ibid.

[114] The current wage rate for municipally employed assistants has been reported as SEK 38. Given the exchange rate cited earlier, this equals an approximate amount of $ 6. Even if a consumer could find a "cheaper" assistant for $ 4 an hour, the costs of several hours a day are not covered by the highest possible allowance of $ 2.548.00. This would allow only 1.75 hours assistance a day.

[115] Reports vary from 25 different persons a year a consumer might meet, to the most drastic example of 67 different assistants in a single month for one person.
See: Ratzka A.D. (1986) ibid. p. 41

[116] cited in: Ratzka A.D. (1986) ibid. p. 41

[117] Today more than 30 federal laws prohibit disability-based discrimination. See: United States

Commission on Civil Rights (1983) *Accommodating* p. 46

[118] 42 U.S.C.A. 6000-81 (1983 & Supp.V 1986) hereinafter cited as "DDA"

[119] "Developmental disability" is a phrase comprising various—mostly mental—disabilities. Impairments that cause substantial functional limitations in three or more of the following areas: self-care, language, learning mobility, self-direction, capacity for independent living and economic sufficiency. The disability must have started before the age of 22 and be likely to continue indefinitely.
42 U.S.C.A. 6001 (7);
U.S. Commission on Civil Rights (1983) *Accommodating*, ibid. p. 59

[120] 42 U.S.C.A. 6010 (1)-(2)

[121] Public Law 94-142 codified in 20 U.S.C.A. 1400, 1412 (1),(5)(B) and regulated in 34 C.F.R. Part 300, 300.132;

[122] See: U.S. Commission on Civil Rights (1983), ibid. p. 58;
Mayerson A. 1981) "Education Opportunities For Disabled Children" in: Disability Rights Education and Defense Fund, Inc. (ed.) *Law Reform In Disability Rights* Vol. II, Berkeley, CA, Part D;

[123] Division 4.5 of CAL. WELF. & INST. CODE, Sec. 4502(a) (1982)

[124] *Rouse v. Cameron* 373 F.2d.451 (D.C.Cir, 1966); *Welsch v. Litkins* 373 F.Supp. 487 (D.Minn.1974); *Pennhurst States School v. Halderman*, 466 F.Supp.1295 (E.D.Pa.1977); *Matter of Commitment of J.L.J.* 481 A.2nd.563 (N.J. Super A.D.1984)

[125] 101 S.Ct. 1531

[126] 457 U.S.307 (1982)

[127] Id. at 317

[128] Id. at 307

[129] *Clark v. Cohen*, 794 F.2d 79 (3d.Cir. 1986), cert. denied 107 S.Ct. 459 (1986); *Thomas v. Morrow*, 781 F.2d.367 (4th.Cir.1986); cert. denied 106.S.Ct. 1992 (1986) and 107 S.Ct. 235 (1986)

[130] *Phillips v. Thompson* 715 F.2d 365 (7th. Cir. 1983); *Renni v. Klein*, 720 F.2d. 266 (ed. Cir. 1983); *Society for Good Will to Retarded Children v. Leisz v. Kavanagh* 807 F.2d.1243 (5th Cir. 1987); *Gieseking v. Schafer* 672 F. Suppo.1249 (W.D. Mo. 1987);

[131] Mental Health Ass. in Cal,. v. Deukmejian 233 Cal.Rpt. 130, (No substantive right in Lanterman-Petri-Shore-Act), *In re C.B., F.C., J.J. and L.K.* 518 A.2d 366 (Vt.1986), (Statutory right to least restrictive alternative does not apply if community-facility is unavailable)

[132] For a deeper discussion, see:
Costello J.D., Preis J.J. (1987) "Beyond Least Restrictive Alternatives: A Constitutional Right to Treatment for Mentally Disabled Persons in the Community" in: *Loyola of Los Angeles Law Review* 20, 1572

[133] Rehabilitation, Comprehensive Services, and Developmental Disabilities Amendment of 1978, Pub.L.No. 95-602, titlI, 92 Stat. 2955

[134] Pub.L.No. 93-122, 87 Stat.355; codified in 29 U.S.C. 701 et.seq., (1976 & Supp.V 1981)

[135] Funding under Title VII part B requires that these centers are operated under the concept of consumer involvement. Disabled persons must be significantly involved in policy direction and management.
See: National Council on the Handicapped (1986) ibid. p. 45

[136] National Council on the Handicapped (1986) ibid. p. 45

[137] Zukas H. (1985) *Summary of Federal Funding Sources for Attendant Care.* World Institute on Disability, (ed.), Berkeley, CA

[138] For instance in FY 1978 the overall health expenditure of the private sector amounted to 111 billion dollars whereas the public sector spent 76 billion dollars on health programs; Racine D. (1986) ibid. p. 32

[139] For instance in FY 1978 the overall health expenditure of the private sector amounted to 111 billion dollars whereas the public sector spent 76 billion dollars on health programs; Racine D. (1986) ibid. p. 32

[140] Title XVIII of the Social Security Act

[141] Title XIX of Social Security Act

[142] see infra

[143] by 1920, all but six states had their own worker's compensation programs; today 55 programs are in operation. U.S. Government Printing Office (1986) "Social Security Programs in the United States", *Social Security Bulletin, January 1986/Vol.49, No. 1*, p. 28

[144] (generally 66 2/3%);
U.S. Government Printing Office (1986), ibid. p. 30.

[145] U.S. Government Printing Office, (1986) ibid. p. 31.

[146] U.S. Government Printing Office (1986), ibid. p. 14.

[147] Title XVI of the Social Security Act, which was amended in 1972 and replaced the categorical Federal-State program for the needy, aged, blind and disabled persons. See: U.S. Government Printing Office (1986) ibid, p. 50; La France, (1979), ibid. 20

[148] National Council on the Handicapped (1986) *Toward Independence. An Assessment of Federal Laws and Programs Affecting Persons with Disabilities—With Legal Recommendations.* U.S. Government Printing Office. Washington, D.C., p. 56

[149] U.S. Government Printing Office (1986), *Social Security Bulletin, January 1986/Vol. 49, No. 1,* p. 50

[150] WID, (April 1987) "Executive Summary of the National Survey of Attendant Service Programs in the United States", *Attending to America, Personal Assistance for Independent Living,* Berkeley, CA

[151] 38. U.S.C.A. 310,331 (1979 & Supp.V. 1986)

[152] U.S. Government Printing Office (1986), ibid. p. 42

[153] U.S. Government Printing Office (1986), ibid. p. 42; National Council on the Handicapped (1986), ibid. p. 56

[154] Litvak S., Zukas H. et.al. (1987) *Attending to America.* ibid. p. 85

[155] 1) 42 U.S.C.A. 1395 (1983 & Supp. 1986);
2)42 U.S.C.A. 1396; (1983 & Supp. 1986);
Publ.L. 97-35;
42 U.S.C.A. 3001;3021 (1983 & Supp. 1986)

[156] Zukas H. (1985) *Summary of Federal Funding Sources for Attendant Care,* ibid.

[157] Commerce Clearing House, Inc. (1987) *1987 Medicare Explained,* CCH Editorial Staff Publication, United States, p. 60

[158] ibid. p. 60

[159] ibid. p. 66

[160] ibid. p. 129

[161] ibid, p. 137

[162] Zukas H. (1985) *Summary of Federal Funding Sources for Attendant Care,* supra

[163] Zukas H. et al. (1987) *Attending to America,* ibid. p. 20;
The National Study Group on State Medicaid Strategies (1984) *Restructuring Medicaid: An Agenda for Change.* (Background Papers) p. 12 (hereinafter cited as "Restructuring Medicaid")

[164] *Restructuring Medicaid* (1984) ibid. p. 12

[165] *Restructuring Medicaid* (1984). Background Paper #4 "The Role of Medicaid in the Provision of Care for the Developmentally Disabled: Issues & Alternatives", p. 120

[166] 42 CFR 440.70 and 440.170(f);
Zukas H. (1984) *Summary of Federal Funding Sources of Attendant Care,* supra.

[167] Zukas H. et al (1987) *Attending to America* supra. p. 20; Zukas H. (1984) *Summary of Federal Funding Sources for Attendant Care,* supra.

[168] *Restructuring Medicaid* (1984) p. 11

[169] Zukas H. et al. (1987) *Attending to America* ibid. p. 20

[170] P.L. 97-35

[171] Zukas H. et al (1987) *Attending to America,* supra, p. 23

[172] *Restructuring Medicaid* (1984) supra. pp. 136/151

[173] Zukas H. et al. (1987) *Attending to America* supra p. 25

[174] enacted in 1975

[175] Zukas H. et al. (1987) *Attending to America* supra. p. 21

[176] California's IHSS (in-home supportive service system) with expenditures of $392 million and a caseload of 112,000 people in FY 85-86 is a notable exception.
See: Zukas H., Leon J., Cone K. (1987) *Attendant Services. Descriptive Analysis of California's In-Home Supportive Services Program,* World Institute on Disability (ed.), 2d. Ed., Berkeley, CA

[177] Zukas H. et al. (1987) *Attending to America,* supra, p. 21

[178] Zukas H. *Summary of Federal Funding Sources for Attendant Care* (1985)

[179] Zukas H. et.al. (1987) *Attending to America* ibid. pp. 22;

[180] 29 U.S.C.A. 794; and 34 C.F.R. Part 104

[181] 45 C.F.R. pt.84 (1982)

[182] 20 U.S.C.A. 1412 (1), 1401 (17) (1978 & Supp.1986)

[183] 20 U.S.C.A. 1401 (17); 34 C.F.R. 300.13; Community Alliance for Special Education [CASE] (1988) *Special Education Rights and Responsibilities.* San Francisco, CA. p. 3; U.S. Commission on Civil Rights (1983) *Accommodating* supra. p. 104; 34 C.F.R. 104.44(d)(1) and (2)

[184] 34 C.F.R. 104.44(d)(2); *Camenisch v. University of Texas* 616 F.2d 127 (5th Cir. 1980), vacated as moot 451 U.S. 390 (1981) (Readers and instructional aids); CASE, (1988) ibid. p. 61

[185] 29 U.S.C. 775(a)(2)

[186] Zukas H. (1985) *Summary of Federal Funding Sources for Attendant Care,* supra

[187] National Council on the Handicapped (1986) *Toward Independence,* ibid. p. 63; Expenditure of FY 1986 amounted to $5.3 million.

[188] Zukas H. (1985) *Summary of Federal Funding Sources of Attendant Care,* ibid.

[189] *Brown v. Board of Education,* 347 U.S. 483

(1956);
However, it should be mentioned that *Brown* has been weakened by *San Antonio Ind. School District v. Rodriguez*, 411 U.S. 1 (1973).

[190] U.S. Commission on Civil Rights (1983) *Accommodating*, ibid. p. 128

[191] U.S. Bureau of the Census (Dec. 1987) *Statistical Abstract of the United States: 1988*, 108th Ed., Washington D.C., p. 406

[192] Zukas H. et al. (1987) *Attending to America* ibid. p. 17

[193] ibid.

[194] ibid. p. 32

[195] ibid. p. 37

[196] ibid. p. 37/38

[197] ibid.

[198] World Institute on Disability. (1988) *A Report to the National Council on the Handicapped on Measures for Promoting Personal Assistance Services for People with Disabilities*. WID, Berkeley, CA. p. 11

[199] Zukas H. et.al. (1987) *Attending to AMerica* ibid. p. 35

[200] ibid. p. 29

[201] ibid. p. 39

[202] ibid. p. 39

[203] ibid. p. 40

[204] ibid. p. 42

[205] ibid. p. 46/50

[206] ibid. p. 53

[207] ibid. p. 53

[208] ibid. p. 55

[209] ibid.

[210] ibid. P. 57

[211] ibid. p. 57

[212] ibid. p. 63

[213] ibid. p. 62

[214] ibid. p. 63

[215] ibid. p. 63

[216] ibid.

[217] 41 of those 77 programs utilizing the IP-model allow relatives to be paid providers in some circumstances; Zukas H. et.al. (1987) *Attending to America* ibid. p. 59

[218] ibid. p. 61

[219] National Council on the Handicapped (1986) *Toward Independence* ibid. p. 45;

[220] supra n. 176

[221] World Institute on Disability (1981) *A Report to the National Council on the Handicapped...* ibid. p. 15

[222] WID estimates that approximately 5.7 million people of all ages, both in and out of institutes, need PAS.
See: World Institute on Disability (Feb. 1988) *A Report to the National Council on the Handicapped On Measures for Promoting Personal Assistance Services for People with Disabilities*, Berkeley, CA, chart 2

[223] West Germany has eleven states, called "Laender"

[224] other fields of the social net which are not covered by these three systems are: 1) child allowances and education allowances; 2) youth assistance; 3) rehabilitation and work support; 4) rent subsidy; and 5) education subsidy. They are of less interest here.

[225] Gitter W. (1986) *Sozialrecht* 2. Auflg., Muenchen;
Stolleis M. (1976) *Quellen zur Geschichte des Sozialrechts*, Reihe: Quellensammlung zur Kulturgeschichte, Bd. 20, (Hrsg.: Treue W.) Geottingen, Frankfurt, Zuerich; p. 29 et.seq.

[226] Gitter W. (1986) *Sozialrecht* ibid. p. 41 et.seq.

[227] Sizialgesetzbuch I [SGBI] 23 (1) (W.Ger.); Reichsversicherungsordnung [RVO] 1236 (W.Ger.)

[228] 21 SGB I; 182 I 1, 185 RVO

[229] Gesundheitsreformgesetz [GRG] 1988 Bundesgesetzblatt [BGB1.]I.2477 (W.Ger.)

[230] 53 GRG

[231] 55 GRG (approximately $375

[232] 185 b RVO

[233] Though Accident Insurance initially was designed to protect injured employees, it now covers a variety of other groups, such as students.

[234] 22 SGB I, 557 (1)(No 6) RVO

[235] 558 RVO

[236] Juergens A. (1986) *Pflegeleistungen fuer Behinderte*. Sozialpolitik und Recht. Bd. 11, Koeln, Berlin, Bonn, Muenchen. p. 25 with further references.

[237] 558 (2) RVO

[238] In 1988 it ranged from DM 426 to DM 1706; Rentenanpassungsgesetz [RAG] 7, 1988 Bundesgesetzblatt [BGB1.]I 581, (W.Ger.)

[239] Juergens A. (1986) ibid. p. 25/26

[240] 558 (3) RVO

[241] Juergens A. (1986), ibid. p. 26

[242] Hauptverband der gewerblichen Berufsgenossenschaften

[243] Juergens A. (1986) ibid. p. 26

[244] Gitter W. (1986) ibid. p. 203

[245] which has to be performed by conscientious objectors as a substitute for military services

[246] regulated by the Opferentschaedigungagesetz (OEG—Victims' Compensation Act)

[247] regulated by the Bundesseuchengesetz (B-SeuchG-Federal Epidemic Act)

[248] Basic pension in case of a 30% degree of disability; disability pension in case of a severe disability which does not allow gainful employment; and economic compensation pensions for those eligible for basic pension who additionally because of their injury have actually less income than before.
See: Gitter W. (1986) ibid. p. 208/209; Bley H. (1988) *Sozialrecht* Frankfurt a.M., pp. 332

[249] 35 BVG

[250] 16. AnpG-KOV vom 27.Juni 1987 BGV1.I. 1554

[251] Juergens A. (1986) ibid. p. 19

[252] 35 (1)(No 5) BVG

[253] 11 (1) BVG

[254] 2 BSHG

[255] The costs for Personal care services, in an outside institutions make up a third of the entire social welfare budget.
See: Schellhorn W., Jirasek H., Seipp P. (1988) *Bundessozialhilfegesetz, Hommentar,* 13. Auflg., Neuwied.Einfuehrung Rz. 53

[256] See for example: Krasney E.-0. (1978) "Empfiehlt es sich, soziale Pflege- und Betreuungaverhaeltnisse gesetzlich neu zu regeln?" in: Staendige Deputation des 52. Dt. Juristentages (Hrsg.) *Verhandlungen des 52, Dr. Juristentages.* Bd.II (Sitzungsberichte). Muenchen, pp. N 34;
In order to restructure the field of personal assistance services, representatives of the Laender and various welfare organizations introduced several drafts into the German Gundestag (parliament) during the last couple of years. Most drafts propose the establishment of a personal assistance insurance scheme. So far, the legislator has not agreed on any of these proposals. Instead a piecemeal approach has been chosen and some existing benefit programs have been extended minimally. One example is the Gesundheitsreformgesetz, mentioned earlier. An overview on the drafts that have been introduced into parliament is given by:
Kopp A., Fichtner O., (1988) *Bundessozialhilfegesetz, Kommentar,* 6. Auflg. Neuwied, 69 Rz. 1a

[257] 68 (1) BSHG

[258] 69 (4) BSHG

[259] 81 BSHG i.V.m. V0 zur Neufestsetzung der Grundbetraege...,BFB1.I 840

[260] Such disabilities as "loss of three limbs" or "loss of both arms", "Severe brain injury", "blind persons" see 24 BSHG i V.m. Durchfuehrungsverordnung [DVO] zu 35 BVG; Blind persons receive a blindness allowance (67 BSHG) that similarly does not require an actual need for PA, but which—among other purposes—is designed to cover PA expenditures.
See: Juergens A. (1986) supra. at 34 with further references.

[261] Judgement of January 31, 1968, Bundesverwaltungsgericht, V.Senat. W.Ger., Bundesverwaltungsgericht Entscheidungssammlung [BVerwGE] 29 p. 108.110; Juergens A. (1986) ibid. p. 174

[262] Commonly services are furnished by contract agencies which are reimbursed by the county government; see infra.

[263] 69 (5) BSHG

[264] The act does not explicitly refer to family or household members. It distinguishes between "assistant" and "special assistant", the latter being referred to as working under employment status.
See: Juergens A. (1986) ibid. p. 31/32

[265] Judgement of June 22, 1978, Bundesverwaltungsgericht,V. Senat, W.Ger., Bundesverwaltungsgericht Entscheidungssammlung [BVerwGE]56 p. 79 (86)

[266] 70 BSHG

[267] For more detailed information on these demonstration projects see: Bischoff H., Rathgeber R. (1987) *Behinderung in Ausbildung und Beruf.* Muenchen. p. 11 et.seq.

[268] Einliederungshilfe, 39 BSHG

[269] mainly in the Land Hessen.

[270] Schwerbehindertengesetz [SchwbG] 5 (W.Ger.)

[271] 14 (3) SchwbG

[272] according to 31 (1)(No 3); II SchwbG and similar provisions in rehabilitation and employment law, such as 55 A Reha.

[273] Bischoff H., Rathgeber R. (1987) ibid. p. 82

[274] For more details see Bischoff H., Rathgeber R. (1987) ibid.

[275] Juergens A. (1986) ibid. p. 161

[276] Juergens A. (1986) ibid. p. 166

[277] Socialdata (1980) *Anzahl und Situation zu Hause lebender Pflegebeduerfiger.* Schriftenreihe des Bundesministers fuer Jugend, Familie und Gesundheit. Band 80. Stuttgart, Berlin, Koeln Mainz, p. 32

[278] ibid.

[279] Bundesregierung (1984), "Bericht der Bundesregierung ueber die Lage der Pflegebeduerftigen".

Bundestagsdrucksache 10/1943 p. 4

[280] Socialdata (1980 ibid. pp. 60/61

[281] ibid.

[282] "ISO", an institute on social research estimates that more than 50% of the centers in West Germany were founded during that time.
See: Institut fuer Sozialforschung und Sozialwirtschaft e.V. Saarbruecken (iso) (1987) *Modellprogramm "Ambulant Dienste fuer Pflegebeduerftige" des Bundesministers fuer Jugend, Familie, Frauen und Gesundheit.* (Zwischenbericht der Wissenschaftlichen Begleitung (Stand: 31.12.1986) p. 59

[283] Deutscher Verin fuer oeffentiche und private Fuersorge (1987) *Bestandsaufnahme der ambulanten sozialpflegerischen Dienste (Kranken- und Altenpflege, Haus- und Familienpflege) im Bundesgebiet.* Schriftenreihe des Bundesministers fuer Jugend Familie, Frauen und Gesundheit. Band 195. p. 37

[284] Deutscher Verin (1987) ibid. p. 67

[285] Bundesgemeinschaft der Freien Wohlfahrtspflege (1984) *Ambulante gesundheits- und sozialpflegerische Dienste der Freien Wohlfahrtspflege* ibid. p. 4; Deutscher Verin (1987) ibid. p. 85

[286] So far, no survey on fees for PAS has been undertaken. Several publications give, however, some examples.
See: ISO (1987). ibid. p. 61;
Ruetter J. (1986) *Die Entstehund und Entwicklung selbstorganisierter Ambulanter Dienste.* ibid. p. 45

[287] Bundesarbeitsgemeinschaft der Freien Wohlfahrtspflege, (1984) ibid. p. 5

[288] Juergens A. (1986) ibid. p. 1

[289] Socialdata (1980) ibid. p. 70

[290] Socialdata (1980) ibid. p. 63: "75% receive help from female family members"

[291] This is true also for those PA centers which were established by the disability movement. As mentioned above, these centers (AHD) were founded as an alternative model of PAS to the "Socialstationen" organized and developed by the welfare organizations. Initially AHD organizers had some reservations about becoming a member of one of the big welfare organizations. But since one condition for receiving funds from the Laender government is such membership, the ideological attitude soon gave way to a more pragmatic position.
For more details see: Ruetter J. (1986) ibid.

[292] Deutscher Verin (1987). ibid. p. 37

[293] which, however excludes certain services such as attendant referral, meals-on-wheels services.

[294] Deutscher Verein (1987) ibid. p. 37

[295] Deutscher Verein (1987) ibid. p. 41

[296] Deutscher Verein (1987) ibid. p. 59

[297] supra p. 21 et.seq.

[298] Deutscher VErein (1987) ibid. p. 90

[299] Deutscher Verein (1987) ibid. p. 80

[300] Ruetter J. (1986) ibid. p. 50

[301] Ruetter J. (1986) ibid. p. 45

[302] Ruetter J. (1986) ibid. p. 52

[303] The case is now pending in court: Verwaltungsgericht [VG] Kassel Aktenzeichen: V/3 F. 2098/86; Verwaltungsgerichtshof [VGH] Hessen, Aktenzeichen: 9 TP 1593/87 (W.Ger.)

[304] Juergens A. (1988) "Rechtliche Absicherung der Pflegebeduerftigen—eine Posse mit 5 Gesetzesentwuerfen" in: Mayer A., Ruetter J. (ed.) *Abschied vom Heim,* AG-SPAK-Publikationen, Muenchen, p. 13

[305] The Land Saarland recently changed its laws with respect to primary education. In general, primary schools are now open for disabled children. But still they do not have a right to integration. It is up to the school district's discretion whether or not to grant admission to a disabled child.
The Land Berlin is considering enacting similar reform laws, while the Land Hessen plans to intensify the child's restriction to segregated special education.

[306] Except for Berlin, which because of its special status has no conscientious objectors. There other financial solutions had to be found.

[307] In 1986 two such centers were founded in Bremen and Hamburg.
See: Mayer A., Ruetter J. (1988) *Abschied vom Heim.* ibid. p. 153/167

[308] WID drafted a model bill—The Personal Assistance For Independent Living Act of 1988—which goes in this direction. It may be hoped that the National Council on the Handicapped will use this draft to influence future personal assistance policy in the United States.
For the bill see: World Institute on Disability (February 1988) *A Report to the National Council on the Handicapped....* supra. pp. 46

[309] supra. chapter I.B.

[310] supra. chapter V.A.

[311] World Institute on Disability (Feb. 1988) *A Report to the National Council on the Handicapped...,* supra, p. 50 et.seq.

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